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ABSTRACT

This monograph consists of five parts: (1) introductory material including a conference overview; (2) papers presented at an international symposium on the topic of ethical issues in disability and rehabilitation as a section of the Annual Conference of the Society for Disability Studies; (3) responses to the symposium, prepared by four of the participants; (4) selected additional papers which offer views from perspectives or cultures not represented at the Denver conference; and (5) an annotated international bibliography. Representatives from 10 countries discussed ethical issues and decision making in disability and rehabilitation. Conference papers include: "Genetic Engineering--The New Eugenics? Evolving Medical Attitudes towards the Quality of Life" (Hugh Gallagher); "Description of the Decision-Making Project" (Daryl Evans); "Treatment and Nontreatment Decisions with Respect to Extremely Premature, Very Low Birthweight Infants (500-750g)" (Ernle Young); "Allocation of Resources and Distributive Justice" (John Mather); "Quality Assurance as an Aid to Ethical Decision Making in Disability Management: Lessons from Recent Ethical Issues Involving Disadvantaged Groups in New Zealand" (Peter Gow); "Disability and Ethical Issues: A Point of View from the Netherlands" (Yolan Koster-Dreese); "Who Shall Live or How Shall They Live? Consumer and Professional Perspectives on Treatment/Non-Treatment Decisions" (Joseph Kaufert and Patricia Kaufert); and "Debates across Social Movements on Reproductive Technologies, Genetic Engineering, and Eugenics" (Theresia Degener). Conference commentaries include: "The Meeting of Disability and Bioethics: A Beginning Rapprochement" (Adrienne Asch); "A Plea for More Dialogue: Commentary on Ethics Conference" (Robert Slater); "Healing Our Wounds" (Martha Lentz Walker); "Theories and Values: Ethics and Contrasting Perspectives on Disability" (Harlan Hahn); and "Current Example of Ethical Dilemma" (Susan Lacetti). Selected additional papers include: "High-tech Medicine Is Basic Care" (Frederick Abrams); "Prevention of Disabilities as a Medical Question" (G. Schioler); "The Ethics of Disability Prevention: A Parent's Point of View" (Mrs. J. Baker); "A Reference Matrix for Issues of Life and Personhood" (Mike Miles); "Nazi Scientists and Ethics of Today" (Isabel Wilkerson); "Ethical and Policy Issues in Rehabilitation Medicine (Hastings Center Report)" (Arthur Caplan et al.); and "Differing Approaches to Prevention of Disability and Treatment of Impaired Infants Creates Controversies Worldwide" (Barbara Duncan). (JDD)

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Ethical Issues in Disability and Rehabilitation

report of an international conference

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Ethical Issues in Disability and Rehabiltation

report of a 1989 international conference

Edited by

Barbara Duncan, Rehabilitation International
and
Diane E. Woods, World Rehabilitation Fund

This volume is published as a collaborative project of the **World Institute on Disability, Rehabilitation International** and the **World Rehabilitation Fund.**

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3) *Responses to the symposium, prepared by four of the participants.*
4) *Selected additional papers which offer views from perspectives or cultures not represented at the Denver conference.*
5) *Annotated International Bibliography.*

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Section 1
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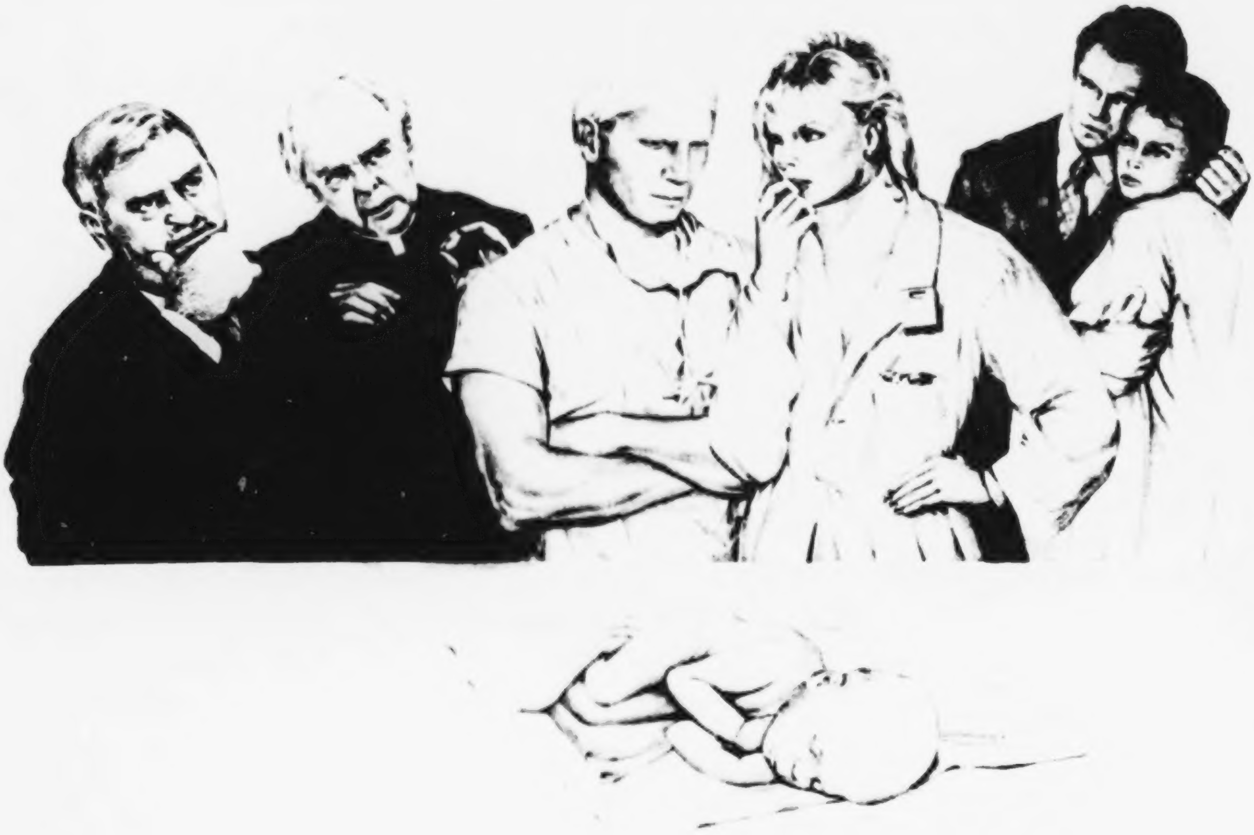


Drawing by Walt Henry, *American Medical News*, June 6, 1986

Preface

World Institute on Disability (WID), Rehabilitation International (RI), and the World Rehabilitation Fund (WRF) are proud to bring you these conference proceedings concerning ethical questions facing disabled and non-disabled people in the United States and around the world today. We hope the material will be as compelling to you the reader as it was for those of us who put it together and participated in the conference. We would like to thank the Society for Disability Studies for welcoming this event as an integral part of its annual meeting and helping to ensure its success.

This conference came about because Hugh Gallagher carried out an IDEAS fellowship from WID and RI to research "The Impact of the Euthanasia Program since World War II on Disability Attitudes, Disability Rights, and the Patient-Doctor Relationship in the Federal Republic of Germany". We believed that his research brought to light several significant issues that could serve as the basis for a stimulating conference and report. We invited the WRF's International Exchange of Experts and Information in Rehabilitation (IEEIR) project to collaborate with WID and RI. These joint efforts have enabled us to put together a conference truly international in scope.

Disabled people, family members, professionals, and societies as a whole are facing many complicated ethical questions. As organizations WID and RI have been participating in discussions concerning some of these complicated ethical questions. We hope this report will give you food for thought about many of the ethical questions we as a society are facing today. These are some of the questions we were thinking about when planning this conference and report: who shall live; who shall die; who shall make these decisions; what, if any, handicappist biases are built into our society that result in prejudicial treatment towards the disabled person; how has the failure of society to provide such services as personal assistance, adequate housing, technical aids, durable medical equipment, transportation, and employment opportunities resulted in disabled people giving up hope for an adequate life and subsequently requesting assistance in committing suicide; is the role the court is currently playing with assistive suicides appropriate; is society obligated to ensure that it is reasonably easy for a person, regardless of the severity of disability, to live a comfortable and safe life in the United States; what role should the disabled community be playing in furthering these discussions; what role should professionals play; how can we determine if the bias of a professional or the court is resulting in detrimental treatment for the person with a disability?

We welcome your feedback on the format of this report. Are you using it? Is this a document that staff and consumers of independent living centers, disability and rehabilitation organizations, professors, researchers and students at universities, women's groups, ethicists, health professionals, religious organizations, labor unions, policy makers etc. find useful? Do you have suggestions for how a document of this type could be more helpful to you?

We hope that this document, and those which we will publish in the future, will enable people to learn how other people around the world are defining and resolving problems facing people with disabilities.

Thank you.

Judith E. Heumann
Vice President
Domestic and International Affairs
World Institute on Disability

Mark Conly
Program Manager, IDEAS
World Institute on Disability

Acknowledgements and Special Note

The co-publishers of this monograph on Ethics would like to acknowledge the role that the Society for Disability Studies played in facilitating the arrangements for the symposium at which most of the main papers which appear in this monograph were presented. Irving Zola and John Seidel were particularly helpful to the sponsoring organizations in convening the International Ethics Symposium at the Second Annual Society for Disability Studies meeting in Denver, Colorado in June 1989.

The World Rehabilitation Fund's International Exchange of Experts and Information in Rehabilitation (WRF-IEEIR) would also like to acknowledge two WRF-IEEIR fellows whose fellowship study-visits in the early 1980's helped to bring to the awareness of the U.S. disability community the need to consider ethical issues more fully.

In 1980, Ruth Purtilo, R.P.T., Ph.D. was awarded a WRF-IEEIR study fellowship for the purpose of engaging her analytical skills as an ethicist to (1) further examine moral reasoning that will support "humane" medical care toward persons with chronic illnesses and (2) evaluate the trade-offs and limits encountered when trying to formulate rehabilitation-oriented and long-term-care policies that reflect widely held ethical ideals and values. This study was carried out in Sweden and her report was so well received by the (then) National Institute of Handicapped (NIHR) that it was decided to invite Dr. Purtilo to contribute to the WRF-IEEIR monograph series, usually reserved for foreign authors. The result was Justice, Liberty, Compassion–"Humane" Health Care and Rehabilitation in the U.S.: Some Lessons from Sweden, published in 1981.

Subsequently, also in 1981, a utilization conference was convened by the WRF-IEEIR to discuss with U.S. ethicists, rehabilitationists and consumers the ideas elucidated in Dr. Purtilo's report and monograph. Mr. Ed Roberts, Co-director of World Institute on Disability and at that time State Director of California's Office of Vocational Rehabilitation, was one of the twenty-five participants at this meeting.

So was Ernlé Young, Ph.D., Chaplain and Senior Lecturer in Ethics at Stanford University, who later in 1983 applied for and was awarded a WRF-IEEIR fellowship to investigate societal provision for the long-term needs of people with disabilities in Great Britain and Sweden relative to decision-making in new-born intensive care units.

Because Dr. Young's report was prepared at the time of growing interest in Baby Doe and "hot-lines", it was again decided to publish his report in the WRF-IEEIR monograph series and to include a variety of "voices" in response to his report in a commentary section in the monograph. Thus, this controversial topic was aired and a cross-section of persons concerned about these issues in the U.S. had the opportunity to speak out.

So the WRD-IEEIR has a tradition, as it were, to engage in dialogue around ethical issues related to disability, which made the offer to join in the co-sponsorship with World Institute on Disability and Rehabilitation International of the conference that sponsored this monograph one we couldn't refuse.

Therefore, we would like to acknowledge and thank both Ruth Purtilo and Ernlé Young as those individuals who promoted considerable interest in ethical issues in the U.S. disability community in the early 1980's. Also, we would like to express our appreciation to NIHR, now the National Institute for Disability and Rehabilitation Research (NIDRR) for its encouragement and support these early international fellowship exchanges which stimulated considerable interest in Ethics.

The continuing support by NIDRR for the International Exchange of Experts and Information in Rehabilitation and now the IDEAS project has made it possible to bring to the U.S. disability community ways of thinking about disability that come from other countries.

We are indebted to Hugh Gallagher whose IDEAS fellowship study was the stimulus for the June 1989 conference which brought together all of the individuals whose papers are presented in this monograph.

To all of those meeting presenters, participants and contributors to this monograph we express appreciation for providing us with material that we feel certain will make it possible for this extremely important dialogue to continue.

James F. Garrett, Ph.D.
Vice President
World Rehabilitation Fund

Diane E. Woods
Project Director
International Exchange of Experts and
Information in Rehabilitation

Conference Overview

Following is a summary of the key issues presented at the conference, reprinted from the International Rehabilitation Review, Vol. XL, Nos. 2 & 3, written by Barbara Duncan, Assistant Secretary General, Rehabilitation International

Doctors, Disabled People and Bioethics Specialists Debate in Denver

Are there parallels between the eugenics movement of yesterday and the genetic engineering momentum of today? Is society ready to accommodate the choices presented by genetic engineering? Who is making the decisions about medically treating or not treating infants with severe impairments? If rationing of health care is on national agendas, who is advocating for the disabled population to receive equity? How do rehabilitation centers decide which clients are allocated medical and vocational services? Are people with disability expertise adequately represented on bioethics committees?

A group of approximately 60 participants from 10 countries met to discuss these and other ethical issues in the disability and rehabilitation fields at an international symposium held in Denver, Colorado, USA. The symposium, which took place June 23-24, was developed to provide a forum for suggestions on how the disability constituency can become more active and influential in groups and processes impacting on decisions in the bioethical arena.

Sponsors

Cosponsoring the meeting were the World Institute on Disability, Rehabilitation International and the World Rehabilitation Fund. The Symposium was a joint activity funded by the international grants awarded to the organizations by the U.S. National Institute of Disability and Rehabilitation Research.

The following article is a summary of the meeting.

Symposium Topics

Main topics of papers and discussions were: lessons from and parallels between the eugenics movement of the early 20th century and the genetic intervention and disability prevention technologies of today; ethical considerations in neonatal intensive care of infants with impairments; treatment decisions in rehabilitation facilities; and reports on disability-related focuses of bio-ethics committees and commissions and health decision groups.

The symposium was divided into five sessions on the following themes: social policy issues; allocation of resources: ethical issues; how can the disability community become more active in deliberations about the appropriate uses of new technologies and health resource distribution in society?; medical technologies: in search of a social consensus; and health and rehabilitation groups: case histories, with the middle session as an open discussion on all related topics.

The following individuals played key roles as speakers or chairpersons:

Frederick **Abrams**, M.D., Chairman, Colorado Health Decisions Project

Adrienne **Asch**, Associate in Social Science and Policy, New Jersey Bioethics Commission

Sheldon **Berrol**, M.D., Chief, Rehabilitation Medicine Service, San Francisco General Hospital

Theresia **Degener**, LL.M., Federal Republic of Germany

Daryl **Evans**, Ph.D., Associate Professor of Medical Sociology, University of Kansas

Hugh G. **Gallagher**, author of *FDR's Splendid Deception* and *By Trust Betrayed: Patients and Physicians in the Third Reich* (Holt 1990)

Peter **Gow**, M.D., President, New Zealand

Rehabilitation Association

Harlan **Hahn**, Ph.D., Dept. of Political Science, University of Southern California

Judy **Heumann**, Vice President, World Institute on Disability

Joseph **Kaufert**, Ph.D., Faculty of Medicine, Dept. of Community Health Sciences, University of Manitoba, Canada

Yolan **Koster-Dreese**, Vice President, Dutch Council of the Disabled

John H. **Mather**, M.D., Chief Medical Officer, U.S. Social Security Administration

Robert **Menter**, M.D., Project Director, Rocky Mountain Regional Spinal Cord Injury System

Robert **Slater**, M.D., Health Decisions USA, National Health Council

Ernlé W.D. **Young**, Ph.D., Chairman, Ethics Committee, Stanford University Hospital

Irving **Zola**, Ph.D., Chairman, Dept. of Sociology, Brandeis University

Program Highlights

The purposes of the Symposium were twofold: (1) to bring together representatives of the medical community involved in bioethical aspects of decision-making, of disability advocacy groups, of rehabilitation professionals, and researchers, to establish a dialogue and (2) to present some information about related developments in several countries. The experiences of the Netherlands, Canada, New Zealand, the Federal Republic of Germany and the USA were selected for presentation.

Hugh Gregory Gallagher, author of a just published book on the relationship between patients and physicians in Germany's Third Reich, presented a paper on "Genetic Engineering–the New Eugenics: Evolving Medical Attitudes towards the Quality of Life." Mr. Gallagher's 1988 investigations in Germany and Austria were supported by an IDEAS* fellowship. Mr. Gallagher's paper for the Ethics symposium concentrated on his concern that just as yesterday's eugenics "experts" were elevated by the Third Reich to institute unmonitored social policy aimed at cleansing a supposedly contaminated national "gene pool", today's genetic engineering specialists and the supporting bio-engineering industry is moving towards unfettered manipulation of the gene pool of the future. He stated,

> *"In our free society, it is the duty of both the government and the citizenry through a series of checks and balances, both formal and informal, to insist upon the primacy of the public convenience, health, and safety.*
>
> *This point is most particularly true in the case of genetic engineering. The stakes are high and if the game must be played, it should be played fairly. Informed regulations should be equally applied. There should be political attention and public discussion of genetic issues, followed by wide participation in decision making on genetic policy. It cannot be left to the doctors or the scientists."*

John H. Mather, M.D., Chief Medical Director of the U.S. Social Security Administration presented a comprehensive overview of the current U.S. health care system and of public and governmental pressures to capture costs while ensuring some measures of fairness to all. In his paper, "Allocation of Resources and Distributive Justice," Dr. Mather points out that,

> *"The demands of medical consumers and providers seem to be increasingly at odds with the willingness of governments or health insurers to pay the bill. The evidence of a mounting tension has been the increased dissatisfaction of providers as each lobbies for a larger share of limited resources: geriatrics versus neonatal intensive care, AIDS versus preventive medicine, physical rehabilitation versus transplant surgery, mental health versus trauma and emergency care. The struggle seems inevitable with one economist (E. Reinhart) observing the emergence of 'bad manners at the health care trough.'"*

**International Disability Exchanges and Studies (IDEAS) Project, administered by the World Institute on Disability and Rehabilitation International.*

Daryl Evans, Ph.D. is Director of the Decision-Making Project, a five year federally sponsored investigation into the social ramifications of the "Baby Doe" cases (involving withdrawal of treatment for severely disabled infants). He stressed that,

> *"With health care rationing more discernible in many settings, laws designed to protect the rights of citizens with disabilities–some of whom require great material and technological resources to survive–may be all that stands between the provision of medical care for these persons and a reemergence of some of the more untoward aspects of the eugenics movement."*

Dr. Evans' report concentrated in part on how parents arrive at their decisions regarding medical treatment for their infants with impairments. He commented,

> *"Perhaps, if these parents were to look into a societal mirror more willing to nurture their hope, their determination, even their happiness, we might take the greatest step in destigmatizing disability, and transcending the need for 'Baby Doe' Amendments."*

Ernlé W.D. Young, Ph.D., Chairman of the Ethics Committee of Stanford University Hospital, California, presented a paper on "Treatment and Non-Treatment Decisions with Respect to Extremely Premature, Very Low Birthweight Infants (500-750 g)." Dr. Young reported on trends he had observed in a World Rehabilitation Fund International Exchange of Experts and Information fellowship to Sweden and England. In brief, trends noted were: in Sweden the tendency was essentially not to treat vigorously infants under 750 grams unless strong countervailing evidence was present; the British approach could be summarized as beginning treatment and then re-evaluating the decision regularly on the basis of clinical indications; and the USA approach as one which encourages vigorous treatment for all infants until it is clear they are not being benefitted or are actually being harmed. Concerning the future, Young concludes:

> *"As a society, we need to redefine the nature and significance of autonomy in the context of medical care. Surely it does not give to the patient or, in the case of the neonate, the patient's surrogate, the right to practice medicine without a license–become involved in the technical decisions that caregivers alone are properly able to make. Surely autonomy is inherently limited by considerations affecting the community. . . And surely autonomy requires that the relationship between caregivers and parents be collaborative or mutualistic, with parents helping to define the overall goals of treatment but not necessarily becoming involved in medical decision-making. As inappropriate as is benignly-intended paternalism on the part of physicians in our time is unbounded autocracy on the part of the recipients of medical care–in asserting that either more or less be done for the infant than seems to be medically indicated. Both extremes reduce either the parents or the caregivers to subservience. But once physicians and parents, together, have agreed to a strategy for treatment or nontreatment, this ought not to be subject to arbitrary veto by interested third parties–whether pro-life lobbyists or federal bureaucrats. If this be not conceded, it is difficult to see how we can both honor and respect the limits of the principle of autonomy."*

Open Forum

An open forum evening session took place on June 23 to allow the participants time to explore some of the more controversial issues in an informal setting. The session was co-chaired by Prof. Harlan Hahn and Ms. Judy Heumann. The issues which came to the fore included: (1) fear that the new genetic engineering momentum is leading societies to expect that the human body is "perfectable"; (2) concern that the expenditures on disability prevention machinery (research, personnel, equipment) will far outweigh the support offered to families with disabled members; (3) the need to improve information to demystify disability and dispel the folklore that life with a disability is a tragedy, characterized by persistent sorrow; (4) the importance of allying with other groups (such as the elderly) who feel threatened by the new emphasis on "allocation or rationing of limited health resources"; and (5) the importance of training people with disabilities in bioethical issues so they can serve on medical ethics committees.

Views from Netherlands, Canada, Federal Republic of Germany

Mrs. Yolan Koster-Dreese, Vice President of the Dutch Council of the Disabled, based in Utrecht, Netherlands, described her experiences as a representative to recent international meetings on ethical issues and the health and disability field. She outlined her perception of the major ethical dilemmas and why it is important that disability advocacy organizations become involved in these issues. She emphasized:

> *"It is debatable whether a social consensus will ever arise around the ethical dilemmas with which we are confronted because of the rapid developments in the natural sciences. For the first time in the history of mankind it is possible to influence* the form of life: *fundamental involvement both before conception and during pregnancy as well as in the later stages of life is now possible by means of manipulation or replacement. This technical ability must be seen against the background of current medical practices. This medical practice is based on two pillars, namely epidemiology and the urge to treat, to execute a therapy. On the basis of epidemiology it is determined what should be considered as "defective" and current medical training ensures that a doctor will want to treat such defects. This, added to the government view that health is an absence of illness, opens a new Pandora's box. It would appear that just about everyone has been dragged along into the "eternal life syndrome" and the drive for "perfection". From an old socialistic dream that society is makeable we have now landed in an individualistic dream, or perhaps nightmare, that life is makeable. This dream leaves little or no room for "being different". And because "being different" is the basic point of departure of an organization such as the Dutch Council of the Disabled, we now experience serious problems."*

She also listed some possible future scenarios:

> *"If everything develops according to the expected trends then we will soon know a great deal about the expected defects, the cause or origin of sicknesses and defects, and about the susceptibility some people have to certain types of sicknesses and defects.*
>
> *At the society level, decisions may be taken based on this new information. I will try to illustrate this with a number of examples.*
>
> *a) The government says it supports the ability of its citizens to choose in freedom, but at the same time takes such measures that the level of health care drops, so that it becomes especially "unattractive" for parents to allow a child with a handicap to be born.*
>
> *b) Insurance companies will base their tariffs on hereditary information.*
>
> *c) In dividing up the funds in the health-care sector, someone with a favorable prognosis will be more eligible for life-increasing or quality-improving treatment than someone not expected to live much longer: he would be a bad investment."*

Theresia Degener, LL.M. of the Federal Republic of Germany presented her views as a member of Finrrage (Feminist International Network of Resistance Against Reproductive and Genetic Engineering) and of the Federal Republic of Germany's Forum of Disability Groups. Finrrage, comprised mostly of scientists, lawyers, health specialists, sociologists, etc. has members in approximately 30 countries who participate in conferences, political fora, and parliamentary discussions about human genetics and reproductive technologies. Following is a summary of the Finrrage outlook.

> *"Women of Finrrage believe that what is promised by those who support these technologies, i.e. that these new technologies*

> *enable women to exercise greater control over their reproduction and thus give them greater liberty–is false. Rather, the organization feels that these technologies deprive women of control of what has been their domain: childbearing and motherhood. Women to whom these technologies are applied, who 'consume' these new reproductive technologies find themselves reduced to egg donors, (surrogate) wombs, fetal environments, reduced to interchangeable raw materials in the process of human reproduction. Women regain the status of personhood only when it comes to the point of making selective (and mostly eugenic) choices, such as selective abortion...*
>
> *And all women are left with is being in charge of quality control over their offspring. Having a disabled child isn't a true option to them. Every woman knows the social status of disabled people and their families all over the world: it is determined by discrimination, being foreclosed from the mainstream of society and being denied basic rights."*

Ms. Degener, whose impairment was caused by thalidomide, also described activities of West German disability groups which actively protest against professional discussions of disability prevention campaigns and policies without the involvement of advocacy organizations.

Joseph M. Kaufert, Ph.D. of the Department of Community Health Sciences, University of Manitoba, Canada, presented a paper entitled, "Who Shall Live or How Shall They Live: Biomedical Ethics, the Consumer and the Rehabilitation Professional." Prof. Kaufert's central concern is that much of today's ethical debate in the medical field is focused on the "individual's right to die balanced against the availability of life supporting machinery and the obligation of the physician to preserve life."

He feels that equal emphasis should be placed on the ethical aspects of assuring a certain "quality of life" to those individuals who will survive (chronic illness or disabling conditions), but require long term care and technological support. He emphasized that,

> *"Community care decisions are less clear cut, but they are also less visible. From the point of view of an ethicist, they lack the drama and clear choice points associated with turning off a life support system. Yet, for consumers faced with the loss of independence and move to an institutional setting, the withdrawal of technological supports may be critical not to survival per se, but to many forms of meaningful survival as determined by the quality of their lives....*
>
> *While we may be acquiring the right to determine when we will die, we are all (the temporarily able-bodied as well as those who are not) losing the right to determine how we will live independently and with dignity."*

Peter J. Gow, BMedSc, FRACP, FACRM, President of the New Zealand Rehabilitation Association, delivered a paper on "Quality Assurance as an Aid to Ethical Decision-Making in Disability Management: Lessons from Recent Ethical Issues Involving Disadvantaged Groups in New Zealand." Dr. Gow's paper provided a number of illustrations of recent ethical problems in New Zealand service provision and descriptions of their resolution. Examples included deficient medical services offered to people with mental illness and a case of persistent undertreatment of a group of women with cancer. His paper also suggested means to set standards in the future, as follows:

> *"The means by which rehabilitation service development groups and service advisory committees might work together with the assistance of a manager to set standards is suggested by Shaw (1987) as follows:*
>
> *'Define the subject...*
>
> *Research the common wisdom...*
>
> *Assess local practice...*
>
> *Reconcile the difference...*
>
> *Test the guidelines...*
>
> *Adopt the guidelines as standards'.*
>
> *In summary, both quality assurance and ethics are intimately linked with the rights of the human individual and his or her interdependence with society. The task of all of us, as providers and consumers of services, is to*

work together to determine the criteria and standards which will provide at least the basic requirements of a meaningful life and the outcome measures to monitor the success of interventions which society introduces to achieve these. We are then in a position to negotiate rationally with those responsible for the allocation of funds, in order that these standards may be met in the most cost-effective manner. With the consumers providing input into the factors which will provide them with good quality care, service providers accepting thes responsibility to deliver this care, and health economists taking note of these principles, it should be possible to provide the most cost effective means to deliver good quality care of an acceptable standard at an affordable cost. By means of formal monitoring with quality assurance programs dedicated to correcting identified deficiencies, the requirements of ethical decision making and social justice should be achieved."

Concluding Session

The fifth session featured presentations by medical specialists who also have responsibilities on hospital ethics committees or with health decision groups.

Robert Menter, M.D., Project Director of the Rocky Mountain Regional Spinal Cord Injury System and Ethics Facilitator for Craig Rehabilitation Hospital, showed a videotape of discussion of a Craig case requiring an extraordinary level of involvement of the ethics committee. Although it is difficult to summarize the tape briefly, the case involved a person who had simultaneously become a high-level quadriplegic and lost his wife through a vehicular accident. Deeply depressed, the man wished to commit suicide and after intensive therapies provided by the hospital staff had no effect on his outlook, his suicide was staff-assisted.

Many of the Conference participants objected to the handling of the situation. The most often voiced criticisms were that: the tape did not indicate that people with high level quadriplegia had been brought in as role models to illustrate the possibilities of a productive life in spite of the physical limitations, and secondly, the usual period of bereavement for the double-trauma of losing a spouse and physical function, seemed not to have been fully taken into account.

Ms. Adrienne Asch responded that this was exactly the sort of situation which had prompted her participation in the New Jersey Bioethics Commission. Her main objection to the handling of the case was that she felt the rehabilition center personnel in charge had not offered the man a vision of a "good life" in spite of his disability. She felt they could have done this by bringing other people with similar injuries who were living satisfying lives to talk with the patient. Ms. Asch and many participants felt that the tape revealed an attitude held too often by the medical community, including rehabilitation personnel, that life with a disability was a devalued life and one perhaps not worth living.

Other participants felt that the presenting physicians were being unfairly critiqued for their handling of an unusually complex situation. Dr. Frederick Abrams reminded the group that, "Ethics is the logic of tragedy. No one can leave an ethical dilemma feeling happy."

After a period of somewhat heated exchange, IDEAS Project Director Judy Heumann closed the conference, stating that this first international opportunity to bring together a select but diverse group of specialists on ethical issues had shown that the need to continue the dialogue was crucial and that the topic would remain high on the agenda for the future.

Symposium Proceedings

The sponsoring organizations agreed to publish jointly the proceedings of the symposium.

The NIDRR grants to the sponsoring organizations enabled financial support of several speakers from outside the USA. The symposium was also utilized to showcase two research travel grants awarded by the organizations.

Foreword

"Go into the street and give one man a lecture on morality and another a shilling, and see which will respect you most."

Samuel Johnson

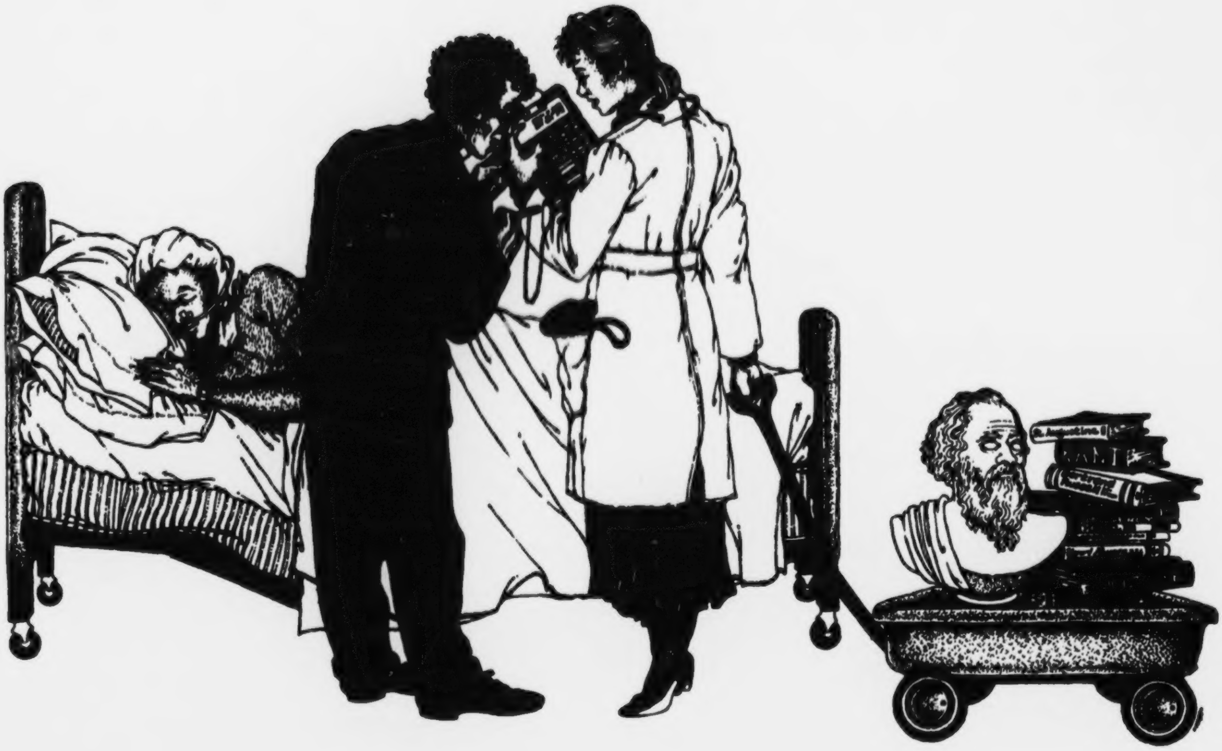
The convening of a conference on Ethics and Disability must, at first blush, appear to many to be an unnecessary endeavor. Of course, everyone recognizes the first claim the disabled person has on the allocation of resources by society for the alleviation of suffering and sustaining them at the maximum level of functional independence. Wrong; the historical evidence is such that President Bush is entirely correct in calling for a "kinder and gentler nation" and this call will need to be heeded by everyone in meeting the needs of the disabled population.

Consequently, it is probably overdue to have held a conference to explore "Ethical Issues in Disability and Rehabilitation: How are Decisions Made?" with the participation of an international faculty and attendees. The topics discussed, are pertinent to the several and various aspects of ethical decisions for, by and with the disabled. The papers, when presented and as reflected in this volume, demonstrate an interesting balance between the theoretical and practical, the academic and pragmatic, scholarly inquiry vis-a-vis strident advocacy.

The collaborating organizations, World Institute on Disability, Rehabilitation International and World Rehabilitation Fund are to be congratulated on giving such a great impetus to bringing these issues of vital interest "out of the closet." Also, the National Institute for Disability and Rehabilitation Research, U.S. Department of Education is to be commended for its foresight in providing the support for initiating this international exploration of these cross-cutting concerns. Hopefully this beginning can be moved forward with a simultaneous addressing of the need for sound ethical constructs as well as the continuing involvement of the disabled themselves.

John H. Mather, M.D.
Chief Medical Director
U.S. Social Security Administration

Section 2
Conference Papers



Drawing by Susan Wise, *American Medical News*, October 24/31, 1986

Genetic Engineering–The New Eugenics? Evolving Medical Attitudes Towards the Quality of Life

by Hugh Gregory Gallagher

Part I

Genetic Engineering–the New Eugenics

Science is difficult to define, but central to any definition of science is surely data that is both measurable and replicable. The material produced in the name of eugenics was, for the most part, neither measurable nor replicable.

Webster's defines eugenics as the "science which deals with influences that improve the inborn or hereditary qualities of a race." The definition itself illustrates eugenics failing as a science: what constitutes improvement of a race was a value judgment made by the eugenic scientists, according to the values and standards of their place and time. Which personal, ethnic, or "racial" qualities are "inborn and hereditary" and which are not, was a question largely unanswerable in the 1930's and by no means satisfactorily answered today. As for the concept of race, there is no ethnological term more subject to confusion and disagreement.

Eugenics purported to be a science, but it was not: it was a value system.

It has been said that the underlying purpose of the eugenics movement was to make the world safe for white, Anglo-Saxon, Protestant gentlemen. The eugenicists told each other they sought to reduce or eliminate human suffering–vice, crime, stupidity, ugliness, and inherited disease–through various selective breeding policies. As part of the process, the eugenicists categorized and graded mankind. White people were better, superior to black people; North Europeans were superior to South Europeans; men were better than women; educated people were better than non-educated; fit people were better than disabled people, and so forth. When eugenicists sought to "improve the qualities" of other people, what they really hoped to do was to make these people over into images of themselves. This may or may not have been desirable. It may have been charitable and up-lifting and, indeed, often it was; nevertheless, it was patronizing, bigoted, ethnocentric, and by no stretch of the imagination could it be called scientific.

When the Third Reich physicians got hold of eugenics, they made it something else–murder.

I have just completed a book on the Aktion T-4 euthanasia program by which the physicians of Germany in the years of the Third Reich participated in a program which killed more than 300,000 of their patients, all of them German citizens, who were permanently disabled or chronically insane. The book, *By Trust Betrayed*, was published by Henry Holt Co., Inc. in January 1990.

The program was called euthanasia, even though those killed were neither dying nor, in many cases, were they in pain. In all cases they were killed against their will and without regard to their legal rights.

The euthanasia program was developed by doctors, managed by doctors, and the killing–final medical therapy, as they called it–was administered by doctors.

Justification for the killing was sought in eugenic doctrine: it would strengthen the race, improve the gene pool, etc.

The program was called euthanasia, even though those killed were neither dying nor, in many cases, were they in pain. In all cases they were killed against their will and without regard to their legal rights.

In reality eugenics was not much more than a set of values intended to govern the making of social policy. Genetic engineering is a far more significant endeavor. Extraordinary advances in man's ability to understand and to alter the genetic code by which the human endowment is passed from one generation to the next will make it possible, soon enough, for the species to shape its progeny.

The disabled resisted the killing. They heroically took part in street demonstrations which were put down with brutal efficiency by the Gestapo.

Some, not many, medical personnel helped the handicapped to escape. Some churchmen spoke out in opposition. In time there developed such a public outcry that Hitler ordered the program halted.

Officially the centralized program was stopped; but the killing went on. Physicians throughout Germany, throughout the war, continued to kill such of their patients as they wished. They killed by the thousands, but because they acted on their own in secret, there are no accurate figures on the number killed. The personnel and the techniques developed in the T-4 program were transferred to the concentration camps, where they became the instruments of the Holocaust.

A "children's program" was operated parallel to the adult euthanasia program. Doctors killed thousands of disabled neonates over more than a six year period. Some doctors continued to kill their infant patients even after the war's end.

After the war many of the very physicians, nurses, and hospitals which had been killing their patients in the program returned to their prewar practice of treating them. Only a few were ever prosecuted; fewer still were ever punished. No apologies were ever made by the medical profession or–so far as I can determine–by individual doctors.

A detailed chronological summary of the T-4 euthanasia program is attached to this paper as Appendix 1.

What was it that made these euthanasia killings possible? There is no one answer to this large, yet elusive, question. Here are three contributing factors:

- The German respect for authority is very strong; it was particularly so in the Third Reich. The physicians' role was Olympian, god-like. This state of affairs encouraged physicians to believe that, indeed, they knew what was right for their patients, and that they had absolute right to direct and control their patients' lives.
- Hitler did not so much authorize doctors to kill their patients, as he impressed upon them that whatever the fate they might choose for their patients, they, indeed, had no fear of persecution or punishment. Physicians' actions were placed beyond the reach of law.
- German society in the 1930's, swept by a kind of demented idealism, was seeking to perfect a Master Race society. Health foods, fresh air, and vigorous exercise were promoted as universal "goods". Youth, health, and sports were glorified; and on the other hand, the disabled and sick were devalued and lumped together with the other "asocials" as a sort of internal enemy whose very existence posed, somehow, a threat to the achievement of a healthy society.

In reality eugenics was not much more than a set of values intended to govern the making of social policy. Genetic engineering is a far more significant endeavor. Extraordinary advances in man's ability to understand and to alter the genetic code by which the human endowment is passed from one generation to the next will make it possible, soon enough, for the species to shape its progeny. It will become possible to stamp out genetically passed disease and to genetically fashion cures for virus and microbe caused disease. It is also conceivable that intelligence, body strength and skill, and even good looks may be genetically programmed. For the first time it will become possible to actually produce–as it was not possible in Nazi Germany–a Master Race.

This knowledge and the power of such knowledge gives genetic engineering an importance far beyond anything attempted under the banner of eugenics.

> *Informed regulations should be equally applied. There should be political attention and public discussion of genetic issues, followed by wide participation in decision making on genetic policy.*

The potential benefit to mankind is great. The social issues raised are quite as great. Genetic engineering will be expensive. Its benefits will not be equally available to all. As a friend commented, "If there is to be a Master Race, who is going to carry out the trash?" And, indeed, within the concept of a Master Race, there lies implicit the idea of a subsidiary race of drones whose purpose is to serve the masters. This is a dangerous idea for a democracy, whose economy is capitalism-based.

It is quite possible that the rich will indulge themselves in what might be called boutique genetics–special ordering "designer" model progeny–while the poor will be unable to afford protection from genetic diseases or treatment with expensive patented genetically engineered drug therapies.

Such therapies, again, promise great benefit, but concomitant with this comes the danger of dreadful accidents–accidents such as the inadvertent creation of an untreatable disease or an uncontrollable organism.

Clearly, genetic engineering presents government–all governments–with a challenge.

The German euthanasia experience during the Third Reich demonstrated that it is unwise in the extreme to exempt the members of a profession–any profession–from responsibility for their actions. When the doctors were given to understand they might kill whom they wished without fear of prosecution or punishment, given our understanding of human nature, it is perhaps not surprising that many promptly went out and did so. The additional fact that doctors were allowed to operate in privacy, away from the cleansing sunlight of public exposure, further sealed the fate of many thousands of chronic patients.

In recent decades, Americans have become increasingly aware of the wide range of ecological hazards produced by industrial society. Disasters such as Chernobyl, Bhopal, potential disasters such as Three Mile Island and Rocky Flats right here in Denver, underscore the point over and over again that it is unwise to expect special interests to regulate themselves in the public interest. Ralph Nader made that point with General Motors; Racher Carson made it with *Silent Spring;* Dr. Frances Kelsey proved it with Thalidomide. Today, Ivan Boesky, Frank Lorenzo, and "Robin HUD" remind us, all over again, of the point. In our free society, it is the duty of both the government and the citizenry through a series of checks and balances, both formal and informal, to insist upon the primacy of the public convenience, health, and safety.

This point is most particularly true in the case of genetic engineering. The stakes are high; the game must be played. It should be played fairly. Informed regulations should be equally applied. There should be political attention and public discussion of genetic issues, followed by wide participation in decision making on genetic policy.

It cannot be left to the doctors or the scientists. President Kennedy was quoted, after the Bay of Pigs, as saying that, "Daddy always warned me not to put my trust in experts." Experts are good at what they are expert in. They are no good at all at integrating their efforts within the larger context of the public weal, nor can they be trusted to evaluate in any dispassionate or impartial manner the risks involved or the safeguards required by their work. If the Third Reich experience of fifty years ago teaches us anything, it is that doctors are not good at social policy.

Part II

The Relevance of the Third Reich Experience to the Disability Rights Issues of Today

There are other situations in which lessons and parallels drawn from the German experience might be applied. Following is a discussion of four such areas of concern: disabled neonates, prosthesis and orthotics, behavioral determinism, and AIDS.

A. Issues Concerning Disabled Neonates

Cruelty to children is universal. Child abuse and infanticide have been practiced, one way or another, at one time or another, everywhere and in every society. Germany had no monopoly.

In the United States in recent years there have been several well publicized cases in which young disabled babies were starved to death by order of their physicians, and a good many more cases which were not so publicized.

The most famous case was that of Baby Doe, an infant born with Down's Syndrome, a disorder of the chromosomes leading to mental retardation and a malformed esophagus. It was not possible to determine in infancy whether the baby would grow up to be slightly or seriously retarded. It was certain, though, that the baby would not grow up at all, unless he had immediate surgery to correct the esophagus problem so that he could eat. This operation is not considered major and has a 85-90% success rate. Baby Doe was unlucky. His physician and his parents decided not to operate. In spite of valid offers of adoption, the courts ruled for the parents, and Baby Doe was starved to death. His physician had testified to the court, "Some of these children. . .are mere blobs. . . These children are quite incapable of telling us what they feel, and what they sense, and so on."

A lesser-known case involved the Doctors Raymond Duff and A.G.M. Campbell of Yale-New Haven Hospital. These doctors in the 1970's wrote widely in the professional journals–the *New England Journal of Medicine*, *Pediatrics*, the *Journal of Medical Ethics*–about their work with disabled children, both the severely impaired and borderline cases such as spina bifida, Down's Syndrome, and physical deformities. It was their work which spoke openly of "death as a management option." They practiced something they called "selective non-treatment," and the criteria they used involved estimates of the child's ability to love and be loved, the concern of the parents for their child, and its chances of institutionalization. These two doctors over a 30 month period oversaw the deaths of 47 of their patients from "selective non-treatment." They concluded, "If working out these dilemmas in ways such as we suggest is in violation of the law, we believe the law should be changed."

> *These two doctors over a 30 month period oversaw the deaths of 47 of their patients from "selective non-treatment." They concluded, "If working out these dilemmas in ways such as we suggest is in violation of the law, we believe the law should be changed."*

From 1977 through 1982, doctors at the University of Oklahoma Health Services Center at Tulsa carried out what they thought was a novel experiment. It was not, of course, so novel. Doctors Richard Gross, Alan Cox, and Michale Pollay published the results of their experiment "Early Management and Decision Making for the Treatment of Myelomeningocele" in the October 1983 issue of *Pediatrics*, the journal of the American Academy of Pediatrics. They explained that the subjects of their experiment were newly born infants with spina bifida. Persons born with this condition require corrective surgery to the spine and the installation of a device called a shunt to drain spinal fluid from the brain. The surgical techniques are not major, but without them the persons will die. Persons with spina bifida are apt to experience further health problems. In later

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life, some must use bracing when walking and some will suffer decreased intellectual development. This cannot be determined with certainty in infancy.

The Tulsa doctors, making use of a mathematical formula devised by pediatric surgeon Anthony Shaw, undertook to decide which of the spina bifida babies under their care should have the life-giving surgery and which should not.

Parents were not told about the formula, nor about the evaluative procedure. They were simply told by the child's physician that surgery was advised–or was not. They were assured this advice was a medical judgment. They were told nothing of "quality of life" estimates.

From the viewpoint of the authors of the report, the experiment was a great success. All 36 of the patients who had received "active vigorous treatment" were alive and doing well. All 24 who, with their parents uninformed consent, had been denied treatment, died. As the article put it, "The 'untreated survivor' has not been a significant problem in our experience." They died as scheduled. In commenting on the Tulsa case, civil rights attorney Martin Gerry, formerly with the Department of Health, Education and Welfare, said "What you have here is a conspircy to commit murder."

This judgment is, no doubt, a harsh one: the medical professionals at Tulsa were, no doubt, well motivated. Nevertheless, the results of what they were doing were the same as the results obtained by the German doctors who participated in the Children's Program.

The doctors, who felt that Baby Doe's future life as a person with spina bifida was not worth living, were basing their opinion upon their own appraisal–as able-bodied people–of the quality of life of a disabled person. There are many people with spina bifida who feel their lives are very much worth living.

Similarly, the physicians of Tulsa who developed an economic formula to determine which disabled babies should be given active assistance to live and which should not, believed that only the well-to-do would be able to supply the care and attention these babies would need to achieve a life worth living. This was the view of well-to-do physicians. There are many disabled people who were raised under poverty conditions by a loving family who have a contrary viewpoint.

B. The Use of Orthotics for Cosmetic Purposes

It has been observed that much of rehabilitative medicine today is devoted to cosmetics–the effort to give the disabled persons the appearance of being "whole" again. This involves such devices as lifelike looking artificial limbs, hidden braces for paralyzed legs. A major example of this is found in the large amount of time and money that has been invested in the attempt, with bracing, harnesses, electrodes, computers, and such, to give the paraplegic person the semblance of being able to walk again upon his or her own legs. Too often such exaggerated efforts represent the doctor's desire to camouflage what he cannot endure. And sometimes, this effort only serves to reinforce the newly disabled person's fear that he is somehow shamefully flawed.

Like the euthanasia program of the Third Reich physicians, such behavior has more to do with the frustration experienced by the doctor over his own impotency (as well as his cultural bias), than it does with the relief or improved well-being of the patient.

C. The Use of Medicine to Alter Behavior

Although eugenics is now a taboo subject, many of the assumptions of eugenics can be

In Nazi Germany, the high economic cost of treating and caring for incurable, disabled people was taught in the schools and brought up repeatedly in the media.

found in the biological determinism of sociobiology. This holds that deviance from a "scientific" norm is ipso facto an abnormality which requires–or at the least suggests–medical treatment.

It is common practice today for physicians to use their medical knowledge and techniques to alter behavior perceived by the community-at-large to be deviant–"hyperactive" children are said to have a disease, Minimal Brain Dysfunction, and placed on drug therapy; lobotomy surgery was used in the 1940's and 50's to halt aggressive or violent behavior; the drug antabuse is used to prevent alcoholics from drinking; aversion therapy, oftentimes unpleasant and painful, is used in an attempt to alter sexual practices deemed to be aberrant.

All of this is, of course, the use of medicine for social purposes. Physicians are applying their skills, not to heal disease, but to alter behavior. This is precisely what Third Reich doctors were about in the 1930's and 40's. They were altering people in conformity to the cultural standards of the day. The issue is complicated; it may, indeed, be useful, even beneficial in social terms, to alter socially deviant or abnormal behavior; but the practice is open to abuse.

D. Acquired Immune Deficiency Syndrome (AIDS)

AIDS presents society with a myriad of difficult issues. There are, perhaps, three major clusters of problems: medical, economic, and social. The Third Reich experience in the thirties and forties illuminates some of the hazards in each of these areas.

1. Medical Analogies

Like chronic disability, AIDS is–at least at present–without a cure. AIDS, like disability, causes the attending physician extreme frustration. The patient is "recalcitrant," as the Nazi physicians used to say, and refuses to respond to treatment. Even more frustrating for the physician is the fact that *all* AIDS patients die. In an age of miraculous medical technology, AIDS forces the physician to confront once again the impotence he feels at being unable to heal.

As the German experience has shown, this can be a dangerous situation for the patient. There, such patients were eliminated by their doctors. In the U.S. they may be turned away, ignored, or given maintenance (or even less) treatment.

It is, perhaps, not surprising that according to the *New York Times*, increasing numbers of American doctors are "helping" their terminally ill AIDS patients to die. "The public would be surprised at how helpful doctors are willing to be," Marty Jones, a Los Angeles advocate of doctor assisted suicide is quoted as saying in a front page story.

2. Economic Analogies

In Nazi Germany, the high economic cost of treating and caring for incurable, disabled people was taught in the schools and brought up repeatedly in the media. In medical society discussions it was argued that by providing disabled people with "final medical assistance" (i.e., killing them), facilities and funds would be released which could better be applied to the treatment of the health problems of the able-bodied, thus improving the health and well-being of society as a whole. Nazi medicine believed the health of the Volk, the German people as a whole, to be more important than the health of an individual. It was the duty of the individual, with the help of the doctor, to keep himself healthy. If he failed to do so, there was a strong sense that it was his fault; he had failed in his duty to the Volk and to the state.

In the U.S., recent years have seen the development of something akin to this sort of thinking. Lung cancer, heart disease, and such, it is said, are caused by the patient's bad habits or failure to keep fit. AIDS is brought on by the sexual or drug practices of the victim. From

There will be pressures, as there were in Nazi Germany, to divert funds and attention away from the "inevitably" dying "asocials" to the more socially beneficent (and less medically frustrating) treatment of those who may respond to treatment.

this, it is an easy jump to the belief that if a person gets AIDS, it is his own fault.

So far, the response to the AIDS epidemic in the U.S. has been neither primarily economics-based, nor blame oriented. In most places, patients have received adequate care and treatment. The costs of this have placed extraordinary burdens upon Medicare, Medicaid, some insurance companies, federal, state and local governments, and, of course, individuals and their families. However, the epidemic has just begun. Many, many more thousands of the infected will soon become active cases, needing treatment. This will place an increasing strain upon funds and facilities already overburdened. The cost of maintaining a major research program into the cause and cure of AIDS has become a federal commitment of the scale of the Manhattan Project in World War II. Already there have been substantial complaints from the advocates of research on other diseases and areas of research who claim that funds are being diverted from their projects to AIDS research. The AIDS epidemic raises genuine economic issues which society and its governments must resolve.

There will be pressures, as there were in Nazi Germany, to divert funds and attention away from the "inevitably" dying "asocials" to the more socially beneficent (and less medically frustrating) treatment of those who may respond to treatment. These pressures are strengthened by the belief–true, often enough–that the AIDS victims have brought their disease upon themselves by behavior considered by many to be immoral.

3. Social Analogies

Fear of the disease may be translated into a fear of the carrier of the disease. In Cuba, persons who test HIV positive are forcibly interned in a camp away from society, just as asocials who committed no other crime were interned in Germany. In the Soviet Union, AIDS carriers have been jailed. Nothing like that is likely in the U.S., but there exists a significant subcurrent of prejudice and fear towards such people.

AIDS patients, like the disabled, are discriminated against minorities. U.S. public attitudes towards "perverts" and "junkies" are not unlike the Nazi attitudes towards the disabled, insane, and "asocials" in the 1930's. With AIDS it is all too easy to blame the victim–particularly, as he is a member of a discriminated against minority.

The analogies with Germany are both real and dangerous. They are enough to make an observer uneasy.

Appendix
The Nazi T-4 Aktion Euthanasia Program: An Outline

I. Origins of program

A. German eugenicists and Social Darwinists from turn of century advocate "strengthening of the Volk," through restricted breeding, internment of retarded and asocial persons, focusing medical attention upon improving the well-being of the healthy with no more than maintenance care for the disabled and the chronically insane.

B. Hitler's personal admiration of eugenics: He said in *Mein Kampf:* The state must sterilize "those who are visibly sick and hereditarily tainted."

C. Physician courts rule on who shall be sterilized, castrated, or aborted. "Not only at home but abroad voices are heard which congratulate the German Reich" on its sterilization program, bragged a German psychiatrist.

D. Widespread expansion of sterilization program to persons with nongenetic conditions–such as amputees, drunks, and "perverts"; unofficial punitive action and the resultant cynical attitude of the public.

II. Creation of program

A. Hitler orders the euthanasia program under cover of war September 1, 1939

B. Program is kept secret to assuage family feelings of responsibility and guilt and to avoid unrest among the patients.

C. Program is conceived as a boon of citizenship, not available to Jews or other non-German nationals.

D. Program is conceived by doctors, administered by doctors. It had been discussed in medical circles since at least 1935. Although secret, most doctors of Germany are aware of its purpose and participate in its procedures.

E. Program is well organized: two administrative agencies are established and a transportation company, the Gemeinnutzige Krankentransportgruppe, is created to carry the patients. Six Euthanasia Centers are set up across Germany.

F. Forms and procedures are prepared; criteria are developed:

1. A form in triplicate must be filled out by an attending physician for each patient in a longterm care facility.

2. A review committee of three doctors passes upon each case–each doctor makes his independent recommendation; the committee as a whole resolves differences of opinion.

3. The recommendations of the committee are reviewed and approved by selected group of distinguished medical university professors.

4. The files of those patients chosen for "final medical assistance" are marked with a red cross.

III. Operation of program

A. Hospitals are notified that selected patients are to be transferred to another facility.

B. Patients are transported to Euthanasia Centers and killed, usually within twenty-four hours of arrival. Initially, they are killed with injections of morphine-hydrochloral or luminal, but experience seems to show that death by CO is more humane; and by personal order of Hitler, this method is adopted.

C. Remains are cremated, placed in an urn, and shipped to patient's family for burial. A letter of condolence and sympathy is sent to family by state officials.

D. System is plagued by foul-ups. Examples: Two urns for a single loved one are shipped to a family. Letter says patient died of appendicitis when his appendix had been removed ten years previously.

E. Program begins small, but grows quickly as it becomes more efficient. Soon, each of the six Euthanasia Centers handles over seventy-five patients a day. Selection process becomes no more than a bureaucratic formality.

IV. End of official program

A. Existence of program becomes common knowledge. Much alarmed gossip: old people become afraid they will be next. Children know and joke about the gassing. Workers in Euthanasia Centers are shunned by local populace.

B. The disabled fight for their lives; run away; seek help from medical staff and from their families. "Wild scenes" of public unrest occur. Townsfolk support patients, fight with police, shout antigovernment slogans. Entire Bavarian town unites in effort to save patients. Himmler and Bormann seek to prevent such incidents.

C. Church leaders openly protest program on moral grounds: Cardinal von Galen provides heroic leadership in opposition to the killing. Army leaders complain of it for reasons of morale.

D. Hitler, bogging down in Russian Campaign, concerned by church protests and needing support of a united society, cancels program at the end of 1941. This is only known case of Hitler responding to church pressure.

V. The "Children's Section"

A. A program to terminate severely deformed or retarded children was created parallel to, but not connected with, the euthanasia program.

B. Program began after Hitler took personal interest in a particular case.

C. Program was not ended by Hitler's 1941 order, but continued–in some hospitals actually well into 1945.

D. All hospitals were required to report deformed babies. Once decision had been made, the children were killed, usually by injection. Some hospitals simply withheld nourishment until death.

E. Parents were not informed of decision, but were allowed to visit their infants before they were destroyed.

F. Program commenced with infants, expanded to include children as old as two, then five, and by the end of the war, seventeen.

VI. Runaway euthanasia

A. After Hitler's 1941 order ending the program, the euthanasia physicians were transferred to the concentration camps.

B. The physicians brought their equipment and their competence for killing and disposing of large number of people. Initially, they killed those camp inmates who were too disabled to work.

C. Teams of these physicians then took to roaming the countryside of Nazi occupied territory, looking for disabled and tubercular "useless eaters," whom they also killed.

D. Soon, the full scale Holocaust was underway.

E. In latter days of war, during the height of the Allied blitz of German cities, institutionalized disabled people were killed to provide beds for the newly wounded.

Description of the Decision-Making Project

by ***Daryl Evans****, Ph.D., Project Director, The Decision Making Project, Associate Professor, University of Kansas*

The Decision-Making Project is a five-year inquiry designed to investigate the manner in which treatment/nontreatment decisions are made in so-called "Baby Doe" cases. The study focuses on how persons decide whether or not to allow life-saving surgical intervention on children born with a life-threatening medical disorder (spina bifida cystica), which, if treated successfully, often leaves the infants with severe disabilities. The work looks not only at the process of decision-making, but at the various processes parents and professionals experience if a successful treatment decision is made—these processes focusing on parental adjustment to various transition in their and their children's lives, and, the interactions between families and health care professionals.

During the five years of the study (1984-1989), five respondent cohorts have been studied: 1) a group of newlyweds with whom a simulation is conducted in which they are told they have just given birth to a child with spina bifida, and are asked to deliberate whether to authorize treatment or opt for nontreatment; 2) actual parents who have made such decisions, who recount the deliberative process; 3) physicians known to have a great deal of experience in such decisions, who discuss spina bifida and a wide range of other disorders that present difficult medical and ethical problems; 4) nurses known to have extensive experience in participating in such decisions, who give accounts of the deliberative process; and 5) persons with spina bifida, who discuss their opinions regarding the "Baby Doe" issue and the particulars of medical intervention decisions about them that they remember. The Decision-Making Project is completing its fifth and final year.

The study uses a grounded approach in developing respondent-emergent issues of importance through pilot studies with each cohort. Further, the project investigates 26 predetermined research issues during each year of the study. These include: 1) child, parent, and family quality of life issues; 2) The emotions associated with treatment/nontreatment deliberative processes and adaptation to transitions; 3) the nature of personal, legal, and social values and standards employed in the deliberative and adaptive processes; 4) the role of the aesthetics of disability in affecting deliberations and adaptations; 5) considerations of the disabled person's potential for contributing to family and social environments; 6) sources of influence, support, and information in the deliberative and adaptive processes; 8) the adequacy and grasp of medical and nonmedical information by all participants in the deliberative and adaptive processes; 9) the effects of previous knowledge of persons with disabilities on the decisions; 10) professional biases in the presentation of information and alternatives for action; 11) the crucial or deciding factors in treatment/nontreatment decisions; 12) where the final responsibility for the decision lies; and 13) the quality of health care for persons with disabilities.

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Information is gathered through interviews which last an average of four hours and have been conducted in five states with 475 persons to date. The same essential procedures are followed for all cohorts, with minor variations to account for certain cohort differences. There are at least three segments to the interview: 1) respondent reactions to a very general question about the treatment/nontreatment decision; 2) subject responses to open-ended, but focused questions relating to the research issues; and 3) respondent completion of a questionnaire relating to the research issues. The interviews are designed to flow from largely phenomenological responses to more researcher-circumscribed questions, and to provide both qualitative and quantitative data. All verbal material is tape-recorded, transcribed, coded, entered into an information retrieval system, and content-analyzed. All questionnaire data are subjected to statistical analysis. Both intercohort and intracohort comparisons typify analysis.

Dissemination of findings was begun late in 1988, when comparisons of the data provided by the first three respondent cohorts could be made. In addition to publishing scholarly work, this dissemination will include didactic materials for parents, professionals, and other persons directly affected by such decisions. In the case of the latter, for example, The Decision-Making Project is producing a series of training audio and video tapes for physicians and nurses to help maximize sensitive and effective communication among all parties to such decisions; a parallel set of materials is being prepared for parents. The findings of the research also are designed to help policy makers fashion legislation and policy about "Baby Doe" types of decisions and to suggest formulations for needed services and improvements in those services that exist.

The Decision-Making Project is being expanded—through a pilot study—to include an investigation of the decision-making processes in treatment abatement decisions about aged populations. That study was completed in March of 1989.

Treatment and Nontreatment Decisions with Respect to Extremely Premature, Very Low Birthweight Infants (500-750g)

by Ernlé Young, Ph.D., Chairman, Ethics Committee, Stanford University Hospital

Statistical data about outcomes and cost of treatment for infants 24-26 weeks gestational age and weighing between 500-750 grams.

For the past ten years and more, neonatologists have been slowly yet surely pushing back the frontiers of viability for extremely premature, very low birthweight infants. Equally steadily, the outcome data for these infants (between 500 and 750 grams) have been improving. The most recent study of follow-up results of intensive care for 68 infants done in our own unit at Stanford (Stevenson, et. al., 1988) yielded the following statistics: the overall survival rate for these infants was 35%; for those infants who had been successfully resuscitated in the delivery room and were then admitted to the intensive care nursery, the survival rate was 50%; 9% of the survivors were severely handicapped; and 36% had remediable disabilities at two years of age. This particular study did not address the question of what were the costs of treating these infants.

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Two years earlier, Maureen Hack, et. al., presented data from six different centers (Hack, et. al., 1986). In this study, the mean survival rate was 33.5%; of those infants surviving, an average of 31% were left with significant neurodevelopmental handicaps. The cost of affording neonatal intensive care for these infants was presented: "The mean length of stay among the survivors was 137 days (range, 71 to 221), and the mean cost of care per infant was $158,800 (range, $72,110 to $524,110)." These figures require adjustment for inflation and do not, in any case, include the long-term, lifelong costs of caring for those with residual handicapping disabilities.

Decision-making in an area of uncertainty.

When the team of caregivers, in conjunction with the parents of babies in the 500-750 gram range, are faced with clinical decisions about treatment or nontreatment, they are inevitably presented with a considerable amount of prognostic uncertainty. There is no way of knowing, at the outset, whether or not a *particular* extremely premature, low birthweight infant will survive. Should the infant survive, there is no way of knowing, at the outset whether he or she will have impairments, or not. The very technologies that save some lives, often inflict harm and suffering on other recipients of intensive care. Statistical data provide us with historical generalities; they provide little prognostic information about unique individuals.

Given the inherent uncertainties of the situation, the caregiving team is caught in a true dilemma. On the one hand, there is the possibility that *by treating vigorously the particular infant before them they will be doing violence to three primary moral principles*—**beneficence, nonmaleficence, and justice.** There are some infants for whom aggressive, intensive care does not prove to be beneficial. Even worse, it may turn out to be harmful—inflicting suffering on the infant being treated without producing any counterbalancing benefit. And if the principle of justice, distributively understood, requires of us to be fair in allocating our limited resources, then expending anything up to a half a million dollars or more on someone whose survival is moot and whose level of functioning, should he or she survive, will be questionable, may have done an injustice to others who more positively could have been helped by the same expenditures—especially if these were used preventively rather than on treating after the fact.

On the other hand, there is the possibility that *failing to treat a particular infant vigorously because of concerns about **nonmaleficence and justice** could violate the principle of **beneficence**.* There is always the considerable concern that an infant not treated vigorously would have survived with aggressive therapy, and survived reasonably intact. Without aggressive therapy, death would have ensued. Do concerns about **nonmaleficence** and **distributive justice** outweigh the duty to attempt to benefit individuals, when there is uncertainty at the outset about whether or not treatment will prove to be beneficial?

This is a cruel dilemma. It is one that neonatologists face constantly in an area of uncertainty. The extremely premature, very low birthweight infant inevitably carries the caregiving team and the parents alike into a zone of ambiguity. Here, as is the case in any genuine moral quandary, the choices may not be between absolute "rights" and "wrongs" so much as between greater and less goods and harms.

Treatment or nontreatment decisions: the legacy of the "Baby Doe Regulations."

Compounding this dilemma is the legacy of the so-called "Baby Doe Regulations." Although the regulations themselves were struck down by the Supreme Court, the "Child Abuse and Neglect" and "Discrimination Against the Handicapped" Statutes, as amended to buttress the regulations, remain in effect. This legacy of the "Baby Doe Regulations" can be viewed both negatively and positively.

Those who believe that neonatologists do not always have the best interests of their patients at heart and are prone to discriminate against people on the basis of perceived disabilities—whether actual or potential—will view this legacy positively. There will be enormous comfort in the fact that in a world where it is always "them" against "us," and where they, the medical caregivers are often among "the bad guys" while we, the opponents of child abuse or neglect and of discrimination against disabled persons are "the good guys," we are not left powerless. We can appeal to these Statutes which remain in effect to prevent neonatologists from neglecting or abusing children or from discriminating against people with disabilities. We can compel them to treat everyone equally, and with equal vigor—ignoring the fact, already stated, that vigorous treatment is in any case going to produce uneven results when it comes to individual cases.

Those who happen to believe that neonatologists are not necessarily any more or less wicked than these rest of mortals and may, if this were to be seriously studied, prove to be gentler, more compassionate, and more caring than most, are likely to view the legacy of the failed "Baby Doe Regulations" negatively. In an area of inherent uncertainty, where there is surely room for disagreement between people of good faith about how best to proceed, the "Child Neglect and Abuse" and "Discrimination Against the Handicapped" Statutes impute bad faith. These statutes suggest that the innate proclivity to harm their patients lying behind the smiling faces of all neonatologists needs to be checked. The way to check this is to redefine nontreatment decisions as child neglect or abuse or as discrimination against persons with disabilities, and then to invoke the appropriate legal remedy.

I am not suggesting that neonatologists who act in bad faith cannot be found, anymore than I would argue that there are not clerics who act in bad faith. But to regard *all* neonatologists as potential abusers of children and as latently callous toward persons with disabilities is surely as grave an error as it is to regard all ordained

> *But to regard all neonatologists as potential abusers of children and as latently callous toward persons with disabilities is surely as grave an error as it is to regard all ordained clergy as cut from the same cloth as the Jim Bakkers and Jimmy Swaggarts of this world.*

clergy as cut from the same cloth as the Jim Bakkers and Jimmy Swaggarts of this world. Yet this is what the Statutes imply. They indicate a mindset in which all neonatologists are guilty until they can prove themselves innocent. The way to prove innocence is by them treating vigorously every neonate in the 500-750 gram range. This ignores all the evidence currently available about uncertainty of treatment outcomes and about the essential beneficence of those who practice the healing arts in the neonatal intensive care setting.

International perspectives on treatment and nontreatment decisions with respect to extremely premature, very low birthweight infants.

In 1984, a fellowship provided by the World Rehabilitation Fund enabled me to do a study of decision-making in neonatal intensive care units in Britain and Sweden, with particular reference to the extremely premature, very low birthweight infant. The findings (Young, 1984) were surprising in three respects. First, the *per capita* incidence of extremely premature, very low birthweight infants in these countries is impressively lower than in the United States. This seems to be because of the availability, in both Britain and Sweden, of good prenatal care for all pregnant women and, in Sweden, of the virtual eradication of the socio-economic causes of prematurity: poor nutrition, inadequate housing, and a consequently harassed lifestyle. Second, the level of lifelong resources available to persons with disabilities for their "normalization" and integration into society is significantly higher than it is in the United States. An ironic indicator of this is the fact that at the very time the "Baby Doe Regulations" were being enacted, our administration was cutting back on services to persons with disabilities and funding for the Women, Infants', and Children Program. Third, in both Britain and Sweden the presumption was *not* to treat vigorously infants weighing less than 750 grams, *unless strong countervailing evidence to treat could be brought forward*. In the absence of this evidence, they would be entitled to *special care* (everything short of assisted ventilation), but not intensive care (which includes respiratory support).

In several important respects, Nancy K. Rhoden, associate professor of law at Ohio State University, advanced and refined these empirical observations (Rhoden, 1986). She delineated three differing national strategies for decision-making in the area of uncertainty we are presently discussing.

Rhoden characterizes our approach in this country as one in which we treat vigorously all extremely premature, very low birthweight infants, until we are virtually certain that they are either *not being benefited* or are actually *being harmed*. Only then are we willing to stop. The effects of erring on the side of life are: we save some who would otherwise have died; we do immediate harm to and inflict long-term suffering on those who survive; and we expend an enormous amount of money on neonatal intensive care (the latest estimates are $2.6 billion annually).

At the opposite end of the spectrum is the Swedish approach of withholding treatment from infants for whom the prognosis is uncertain, at best, or grim, at worst. Rhoden calls this the "statistical prognostic strategy." The net effect is that some are lost who with vigorous treatment might have been saved; that the amount of immediate harm and long-term suffering is minimized; and that limited societal resources are conserved—to be deployed in other, more cost-effective areas.

Between these two extremes is the British approach—starting treatment and then re-

. . . in an area of inherent uncertainty of outcomes, people of good faith will proceed differently, in good conscience making different decisions.

evaluating this decision regularly on the basis of clinical indications of ultimate death or severe brain damage. Rhoden describes this as the "individualized prognostic strategy." The effect of this strategy is to salvage more individuals *per capita* than are salvaged in Sweden, but fewer than we rescue in the United States; to minimize both immediate harm and long-term suffering; and to conserve finite resources to an extent less than is the case in Sweden and greater than is true in the United States.

Doubtless, these national differences are attributable to various factors: socialized medicine in Sweden, national health care in Britain, and the mixed array of public and private funding mechanisms in the United States; religious differences (we appear to have a more vigorous "pro-life" lobby in this country than is evident in either Sweden or Britain); and the substantially larger role fear of legal liability plays in our society than in either Britain or Sweden. Nonetheless, they underline the central point of this paper: **that in an area of inherent uncertainty of outcomes, people of good faith will proceed differently, in good conscience making different decisions.**

In a recent M.Sc. thesis, Steven Harris describes treatment limitation at Stanford (Harris, 1989) in terms similar to what Rhoden calls the "individualized prognostic strategy." "Stanford neonatologists state that they attempt resuscitation for all critically ill newborns and hasten them to the ICN. ... But after initiating intensive care, the staff, with the participation of the parents, appears prepared to curtail aggressive therapy and redirect care to measures that provide comfort for the infant."

Conclusions

These are not so much ending-points as starting-points for an ongoing discussion (within this conference) within our society.

First, we have to question our American lack of interest in prevention (and rehabilitation) *versus* our infatuation with heroic, high-technology, after-the-fact intervention. In so many areas, we appear to be more concerned to catch the horse once it has bolted from the barn than to close the barn door in the first instance. Would not addressing the root causes of prematurity—lack of prenatal care, poor nutrition in pregnant women, homelessness, and drug or alcohol addiction—be more cost-effective than merely treating premature, very low birthweight babies once they arrive in our neonatal intensive care units?

Second, we have to advance toward a more rational view of stopping aggressive therapy, once having started, when it is clear that the principle of *beneficence* is not being served and that of *nonmaleficence* is being breached. In part, this is beyond the control of any of us, for fear of litigation causes medicine to be practiced overly defensively in this country. Until arbitration or some other alternative way of settling legitimate grievances can be substituted for malpractice litigation, stopping once we have started is going to be very much more difficult than not starting in the first place. But in large part the "Child Abuse and Neglect" and the "Discrimination Against the Handicapped" Statutes, as amended to bolster the "Baby Doe Regulations" serve to inhibit decisions to stop once treatment has been initiated—even when *beneficence* is not possible, *nonmaleficence* is being breached, and *justice* is not being served. Two Stanford Neonatologists make this point succinctly: "The relentless application of intensive care to those neonates whose chances of survival are judged to be, '1 in 1000' or, 'without precedent' is in conflict with the charge of alleviating suffering for the majority of neonates. In such a setting, it also becomes difficult to justify the tremendous costs that are incurred. If we fail to introduce some measure of reasoned restraint into our decision-making processes, prolonged suffering and large hospital bills will continue to accompany the uncertainty of our prognosis for a substantial number of very low birthweight infants." (Fischer and Stevenson, 1987)

One thing is certain: when resources become scarce, or are perceived to be scarce, or are relatively scarce, concerns about distributive justice increase in intensity until the point is reached when they can no longer be ignored.

Third, we have to confront the inescapable fact that ours is an era of shrinking resources, and that setting limits is thus inevitable. Already, such respected writers on ethics as Daniel Callahan (1987) and Norman Daniels (1988) are advocating a rationing of heroic, intensive care for the elderly. A recent Brookings Institution study (1989) entitled, "Rationing of Medical Care for the Critically Ill," recommends tightening admission standards to adult ICUs. It seems to be only a matter of time before the threshold of eligibility for very costly, high-technology intensive care for the very low birthweight, extremely premature infant will be raised. The only question is, Who will do this first? Medicare? Private sector insurers? Or the neonatal intensive care team itself? One thing is certain: when resources become scarce, or are perceived to be scarce, or are relatively scarce, concerns about *distributive justice* increase in intensity until the point is reached when they can no longer be ignored.

This leads to a **fourth**, and final, conclusion: as a society, we need to redefine the nature and significance of *autonomy* in the context of medical care. Surely it does not give to the patient or, in the case of the neonate, the patient's surrogate, the right to practice medicine without a license—becoming involved in the technical decisions that caregivers alone are properly able to make. Surely autonomy is inherently limited by considerations affecting the community: none of us, living in society, is free to violate traffic regulations or evade taxes for example. And surely autonomy requires that the relationship between caregivers and parents be collaborative or mutualistic, with parents helping to define the overall goals of treatment but not necessarily becoming involved in medical decision-making. As inappropriate as is benignly-intended paternalism on the part of physicians in our time is unbounded autocracy on the part of the recipients of medical care—in asserting that either more or less be done for the infant than seems to be medically indicated. Both extremes reduce either the parents or the professional caregivers to subservience. *But once physicians and parents, together, have agreed to a strategy for treatment or nontreatment, this ought not to be subject to arbitrary veto by interested third parties—whether pro-life lobbyists or federal bureaucrats.* If this is not conceded, it is difficult to see how we can both honor and respect the limits of the principle of autonomy.

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Allocation of Resources and Distributive Justice

by ***John H. Mather,*** *M.D., Chief Medical Director, U.S. Social Security Administration**

Several years ago the notion of "protecting the medical commons"(1) was described where medicine is compared to a village green upon which the villagers allow their cattle to graze in proportion to the available pasture. If a villager were to put an extra cow to forage on the common, simply allowing that just one more would not damage the pasture, but should all the villagers do the same thing, then the pasture would be destroyed and the herd would die. The metaphor is directly pertinent to the evident disparity between the costs of providing medical care and the ability of economic systems to pay for them. The demands of medical consumers and providers seem to be increasingly at odds with the willingness of governments or health insurers to pay the bill. The evidence of a mounting tension has been the increased dissatisfaction of providers as each lobbies for a larger share of limited resources: geriatrics versus neonatal intensive care, AIDS versus preventive medicine, physical rehabilitation versus transplant surgery, mental health versus trauma and emergency care. The struggle seems inevitable with one economist(2) observing the emergence of "bad manners at the health care trough."

Health Care as a Right

In most developed countries and in many developing countries attaining a "healthy" population seems to be an essential value for that society. Once the basic public health measures have been taken, such as ensuring a clean water supply, the disposal of human waste and establishment of a safe food supply, then the alleviation of distress and cure of disease becomes paramount. This aspect of health care often engenders support for the assertion that "health care is a right."(3) The idea of health care as a right presupposes an obligation of society, providers, politicians, physicians, and others, to see that the right is upheld. Yet, what is the nature of the assertion of a "right:" whether it is a right to "health," which is an ideal state; whether it is a right to "health care," which is a service; or whether it is a right to "equity of access to health care," which is a social policy.

The demands of medical consumers and providers seem to be increasingly at odds with the willingness of governments or health insurers to pay the bill.

It is readily apparent that these terms have various meaning for different people, depending in certain ways on a dispassionate or vested interest in the economic liabilities incurred. In recent years the "price" to be paid for assuring access to medical care, let alone health care, has led to reappraisals of the provision of medical care and its justification in many western societies. In the U.S., where about 11.5 percent of the gross national product is devoted to health care, there is evident concern for health costs being out of control(4). The U.S. auto industry has expressed its deep concern for the payments of health insurance premiums to cover its employees(5). This frustration has extended itself to an admission by U.S. automobile industry executives that their efforts of the past several years have failed. More importantly they are calling for drastic changes in the way the U.S. pays for health care including the merits of national health insurance(6).

The American Public's View

Yet while business and government raises alarm about the mounting costs of U.S. medical

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***Note:** The views and observations are those of the author and should not be construed in any way to be an expression of U.S. Federal policy.

Other countries, most notably Great Britain and Canada, have recognized the necessity that sophisticated diagnostic and therapeutic technologies create significant "costs" and have questioned the purchase of services that produce perceptible, but marginal, benefits at great cost.

care, Americans favor more rather than less health spending(7). Nonetheless, Americans appear to be satisfied with their personal medical care while highly critical of the U.S. health care system. Indeed, a majority favor extending the availability of health care rather than lowering the U.S. expenditures on health care(8). Many surveys have shown Americans critical of the high cost of services and the perception that many people do not have access to medical care.

Thirty-seven million Americans, an increase of six million since 1981, are reported to have had no health insurance in 1988. Within this, 37 million are 12 million children with no health coverage. A recent study by the Harvard School of Public Health and Louis Harris and Associates found that 13 percent of all adult Americans said they needed medical care in the previous year but failed to obtain it(9). This translates into 20 million adults and more than half failed to obtain needed care because it was too expensive including situations where they didn't have adequate health insurance coverage.

Growth in Health Care Spending and Cost Containment

While Americans are generally satisfied with their personal health care situations, some are receptive to a high-quality, lower-cost alternative(10). Most Americans have not been inclined to participate in lower-cost arrangements such as patient provider organizations (PPOs) and health maintenance organizations (HMOs) although there is a suggestion that this is changing. Unless there are major changes in American behaviors, then projecting a 15 percent of GNP devoted to health care spending is predictable(11). The pressure is clearly on to cut government health care outlays—principally in Medicare, Medicaid and public health service programs—which is likely to affect the quality and availability of health care. The mood is one in which the tension between a willingness to devote larger portions of the U.S. "wealth" to health care and the perception of marginal gains through improvements in health status, as currently measured, will result in a reevaluation using terms such as effectiveness, efficiency, benefits, cost-tradeoffs, cost-effectiveness, cost-benefits, et al.(12). All the lexicon of the economists in the context of political debate, necessitates the raising of the spectre of rationed health care and delivery of services.

Rationing and Resource Allocation

As compared to other developed countries the United States has not elected to systematically "ration" health care services but rather has allowed the market place competitive "business" environment decide the mix and availability of services. The cost of medical care, especially hospital care, has been rising faster in the U.S. than general inflation or the growth of the population. Other countries, most notably Great Britain and Canada, have recognized the necessity that sophisticated diagnostic and therapeutic technologies create significant "costs" and have questioned the purchase of services that produce perceptible, but marginal, benefits at great cost(13). While it may be too early to judge the effects of the last eight years, a U.S. government policy of deregulation and market-oriented policies virtually terminated two decades of federal expansion in health care delivery and insurance. The federal policy became one of health costs containment rather than expansion of access to health care services(14). Efficiency, productivity and cost savings have become the "coin of the realm" rather than a commitment to expand access to health care services.

Fairness and Resource Reallocation

Economics has been defined as "the study of how men and society end up choosing, with or without the use of money, to employ scarce productive resources that could have alternative uses, to produce various commodities and distribute them for consumption, now or in the future, among various people and groups in society. It analyzes the costs and benefits of improving patterns of resource allocation(15)."

In the U.S., various attempts under the banner of "Health Decisions: USA" are under way. These community fora may yet grow to satisfy the possibility of fair-sharing in the allocation of resources.

This statement, which includes more than what most would expect to have seen defined as "economics," contains several ideas pertinent to health economics. It embodies concepts of choice or choosing, allocation of "scarce" resources or establishing priorities, measurement of benefits or effectiveness/efficiency calculations. Underlying much of this general definition are clear implications for how health is viewed as a commodity. Indeed, in the market place, the concept of opportunity cost becomes a dominant theme. That is, assuming a scarcity of resources then any choice results in an opportunity forgone in order to give priority to a "needed" program or service. Yet need is a value judgment that even precedes the application of economics and in essence becomes an issue of perception. Also the determination of need is rarely absolute but comparative with decision-making focused "at the margin," that is a choice between "good" things(16).

However "mechanical" the economists would have us believe decision-making is, the questions of justice and equity seem to be more important. In broad terms, in whatever manner health care policy is debated, there seems to be general agreement on a basic achievement of fairness. Fairness can be taken to be an amalgam of equity, ethics and efficiency. The determination of fairness has more to do with making ethical (or moral) choices and ensuring the efficient use of resources.

The notion of fairness has theoretical bases in four essential areas which can quickly be challenged(17).

- **Entitlement Theory.** Each in entitled to what they have as long as it is justly acquired.
- **Utilitarianism Theory.** Serving the greatest good for the greatest number.
- **Maximum Theory.** Duty or wish that the worst off be given high priority.
- **Equality Theory.** Equality of access to services and products.

All the approaches are very interesting, each with its own grain of "truth". None seems to give great insight into fairness in the allocation of resources. Fair-sharing may be a mode of thinking which can bridge the spectrum of health care systems(18). This is not to ignore the overlay of process solutions, including economic/political and medical/scientific(19) or fail to acknowledge the possibility of a national process that requires application of fair-minded principles. It has been suggested that three principles should be considered when medical resources are to be allocated or re-allocated(20).

- policies should be based upon evidence, not opinion or consensus;
- the analysis should state the magnitude of health and economic consequences of all options; and
- the policy should compare the estimates of all outcomes as well as a final recommendation.

This is a very stringent set of principles which, if completed in open forum, may result in the populace coming to grips with the competition to accomplish "good" things. In the U.S., various attempts under the banner of "Health Decisions: USA" are under way. These community fora may yet grow to satisfy the possibility of fair-sharing in the allocation of resources.

Redistribution and Systematic Changes:

In the U.S. 1966 was the year when two broad redistributive programs were initiated by the government: Medicare and Medicaid. The intended beneficiaries were population groups: the aged and disabled (Medicare) and the poor (Medicaid). These two programs have had very broad support in which there is an explicit redistribution of wealth. The beneficiaries, in general, expect to receive benefits in excess of their contributions within the rubric of "social insurance." The equity lies in the ascribing of value and fairness such that those of a higher income, "the losers," pay (taxes) to finance these programs. The expectation of the "losers" is that their time could come, in the form of Medicare eligibility at age 65 or disability benefits, if needed, or that the safety-net will exist if they are impoverished, Medicaid.

There are essentially then, two types of redistributive programs: charitable and universal(21). They are characterized as follows:

- **Charity (Welfare) Programs.** These are specifically designed to assist the poor. Eligibility is according to a "means test" and the program is financed by general taxation. The beneficiaries are "poor" and benefits are borne by those with higher incomes. These programs may be a cash benefit such as Aid to Families with Dependent Children (AFDC) and Supplemental Security Income (SSI). Other programs pay for in-kind services such as housing and medical care (Medicaid).
- **Universal Programs.** These are for a category of individual with an eligibility, regardless of income. The financing may be from general revenues or specific taxes for the narrow purpose of the program. Again the benefit may be a cash benefit such as veteran's disability benefits, workmen's compensation or in-kind services such as Medicare.

While these distinctions are useful for academic purposes it is difficult to translate them into measures or "criteria" for evaluating a system of health care. The U.S. system of health care has been described as pluralistic, at best, and chaotic, at worst. A moderate position concludes that it is a "patchwork" with potential for overlaps and gaps in services and programs. Somewhere between the three observations lies, nonetheless, a concern that more can be done with the same. Yet a conservative U.S. health policy group has observed:

> *"In order to ensure access to the same quality health care system for everyone, adequate resources must be provided to health care providers to sustain an appropriate level of services, both geographically and across types of services. It is clear that there are limits in our ability as a society to pay more and provide more services. ...Budgetary decisions related to Medicare and Medicaid programs, and employer decisions related to private health insurance coverage should be made in consideration of the potential effects on the future quality of the entire health system(22)."*

Just recently another group of conservative scholars at the Heritage Foundation has proposed a *Top-to-Bottom* overhaul of the U.S. health system(23). Among other things proposed is the abolishment of the present Medicare taxes and premiums on the elderly and increasing the Medicare deductibles and the amount of coinsurance paid by those who can afford it. Middle- and upper- income elderly would be responsible for a greater share of their own routine medical expenses, with Medicare paying for major or catastrophic illness. Medicaid would continue to cover the poor, elderly and disabled for costs not paid for by Medicare. The report calls for a separate long-term nursing-home care program for the elderly poor and Medicare vouchers to allow the elderly to buy their own health insurance.

Designing "Criteria" for Systems

The continuous emphasis on the use of financing mechanisms as the determinator of resource allocation bodes ill for consensus

> *"Americans can always be relied on to do the right thing after they have exhausted all the other possibilities."*

building. Even so, an approach which attempts to systematically define the parameters of the debate over the totality of needs might be useful.

Accordingly, the "criteria" that could be used to measure fairness and equity might be defined as accessibility, availability, comprehensiveness and continuity.

- **Accessibility** is used in the context of the provider being accessible for a "first-contact" of interfacing with the health care delivery system, regardless of the presenting complaint.
- **Availability** is used in the context of the practitioner being in the appropriate geographical locale and able to command all the resources needed to managing the presenting complaints.
- **Comprehensiveness** is used in the context of providing a broad range of diagnostic and therapeutic services.
- **Continuity** is used in the context of the practitioner being gatekeeper in the system with appropriate referral of patients/clients to consultants yet maintaining constant.

The "Criteria" and Rehabilitation Services

It must be evident to observers of the U.S. "scene," who are not Americans themselves, that the U.S. is relatively profligate in the use of its wealth, particularly where it seems to foster inequities. Yet, it is a characteristic of a country 200 years old, that its populace is impatient for breaking new frontiers and risking a lot to achieve a personal sense of making it. The U.S. remains the land of opportunity and consequently it is likely to be some time before the notion of constrained resources really hits home and the populace has to determine a shift in its values. It is certainly unclear whether a broad sense of fairness will ultimately prevail or whether the perpetuation of the present competitive mode will continue. Many years ago, Winston Churchill said, "Americans can always be relied on to do the right thing after they have exhausted all the other possibilities." What are some of these possibilities.

- **Accessibility**

While universal access to medical and health care in the U.S. has significantly improved over the past several decades, the determination of success contains a significant irony. The increase in numbers of people reaching old age is a tremendous success story. It is due to improvements in public health, reductions in childhood mortality and disease, new discoveries about diseases and their treatment and changes in personal life styles. The "solutions" which have supported the aging of the population have created a situation now almost universally looked upon as a "problem"—how to meet the needs of this growing population. Most of the elderly live in the community and in their own households. Independent living is the norm, and it is fundamental that the primary goal for the elderly should be the maintenance of the maximum level of independence. The maintenance of both physical and psychological health, of financial security and of continued integration is critical to this functional independence(24).

Nonetheless, aging is widely associated with a gradual decline in the individual's ability to function independently. Longer life is similarly associated with a higher occurrence of disease. Death may shorten the period of decreasing capacity, but for many people there is an inevitable onset of increasing frailty. Much of this frailty can be compensated for if the proper medical and support services are available to the older individual. However, such services must be both timely and coordinated if they are to be effective in maintaining the maximum feasible degree of independence.

In providing health care to the elderly, promotion of the maximum level of functional independence is the fundamental goal. Yet a balance has to be struck, recognizing the predictable decline in an individual's ability to retain independence with advancing age. The paradox is that, to the extent to which services and programs are made available to meet the needs of the elderly, they have the potential for prolonging life, thus increasing both the level and duration of dependence(25).

There certainly are instances of overuse of medical technology at the end of life—prolonging dying rather than prolonging life. But there are also as many instances in which life is saved by an aggressive effort in the face of uncertainty.

This paradox has now become so evident that opinions are being voiced which ask for explicit limits to medical care, based on age(26). The intent is to use age as the basis for rationing the use of expensive and extensive life-sustaining medical treatment. The arguments are enticing when the urging is to consider death as a natural part of life, not to be resisted when its time comes. This concept of a natural lifespan becomes the basis for an apparently "fair" approach to rationing medical care with the proposed "setting limits" of an age (70? 80?) above which no life-supporting medical care would be given.

The immediate past governor of the State of Colorado created a maelstrom a few years ago when he proposed an explicit rationing of medical care for the elderly. The point was clearly made when it was stated "We are proposing not funding transplants, artificial organs, or extraordinary procedures for those over sixty-five."(27)

Implicit in this theme is that this state of affairs is in essence an inter-generational shift of resources with children and youth becoming the "poorest" group(28). Already values are shaped to have one believe that the young, who have not lived a full life, are more useful to society than those now aged who have had their life's course. Inevitably this leads to the conclusion e.g. that an impaired mongoloid child is more valuable than an elderly person with Alzheimer's disease.

There certainly are instances of overuse of medical technology at the end of life—prolonging dying rather than prolonging life. But there are also as many instances in which life is saved by an aggressive effort in the face of uncertainty. No precise diagnostic measure tells a physician the chances of success in the treatment of critical illness. If a patient has, ahead of time, refused heroic measures, the physician can—indeed should—refrain from intervention and allow death to come without a struggle. Such decisions must be made on the basis of clinical judgment, and such decisions are difficult to make.

This "difficulty" leads directly to the argument that since physiologic and prognostic judgments are so difficult to make in the elderly, why not simply base life-prolonging decisions on an arbitrary age limit?

Much could be observed about the "healthy" aged that tends to negate the argument. The pressure for acceptance of the argument is on the premise that declining resources have placed us in a "lifeboat" situation, in which some people must be thrown off the boat if others are to survive. The main rationale advanced for jettisoning persons is on the basis of age, with an implication of an unresolvable infirmity. This approach to rationing on the basis of age may really represent a retreat from ethical standards that removes families, individuals and their physicians from the process of decision making. There appears to be no medical, social or ethical rationale for rationing medical care to a group that is largely responsible for any country's economic growth and prosperity.

- **Availability**

The geographical dispersion of medical, social and health related services in the U.S. is similar to other developed large land-mass nations. One advantage may be the relative "surplus" of physicians in the U.S. which has resulted in smaller and smaller communities having a doctor. This trend may continue although the variety of specialists completing their training may not result in sufficient primary care disciplines. This is critical since most narrow disciplines require a large population to support a practice such as gastroenterology and ophthalmology. Most communities do not have the immediate availability of physical and rehabilitation medicine specialists. Yet availability goes beyond the numbers of practitioners in a community (including allied health personnel, social workers, etc.)

In 1989, the State of Oregon decided to drop coverage in the Medicaid program of organ transplants to spend more on prenatal and other preventive care(29). But after the death of a child waiting for a transplant, the State legislature changed its mind. While the legislature has stood by reinstating Medicaid coverage for organ transplants it is now considering a bill that would prioritize covered medical services even further. Rather than cut eligibility, the state would eliminate coverage of services given lower priorities. The general intent is, with the acknowledgment of limited resources, that the needs of a single person should not be put above the needs of the Medicaid insured group.

Until a few years ago the U.S. had a law which mandated Comprehensive Health Care Planning. The law established in the mid-70s a network of Health Planning Agencies and these State-based entities were funded by the federal government. The essence of the program was to direct an organized geographical dispersion of medical and health care services. Its enforcement powers related to the approval or withholding of Certificates of Need (CON). The CONs were applicable to the building of additional hospital and nursing home beds as well as various discrete diagnostic (e.g., CAT scans) and therapeutic (e.g., cardiac catheterization units) services. These agencies were successful in promulgating and enforcing regulations that limited growth but was not as successful in ensuring that gaps in services were provided. The agency had no powers to insist that the proprietary health industry should develop proposals that would fill the gaps. Indeed in many instances a dearth of psychiatric and rehabilitation services prevailed until Medicare changed its reimbursement mechanisms in 1983. All services, except psychiatric and rehabilitation, were "reimbursed" on the basis of a designated "prospective price" using the diagnosis-related groups (DRGs) methodology. Essentially everything in the health care services delivery side has come to adhere to the competitive model. Ideal lengths of hospital stays, the DRG, are established and there is need to discharge patients quicker and maybe even sicker.

Medicare, even with the catastrophic provision that became law in 1989, emphasizes "payment" for discrete measurable services. The broad availability of services seems to follow the varieties of payment to a very high level of correlation. Little distinction is made between "life-enhancing" and "life-extending" practices. An example of a "life-enhancing" service would be socially oriented adult day care services with an emphasis on maintenance rehabilitation with strong psycho-social and recreational services. A "life-extending" service would be high-tech home care services with an emphasis on restorative rehabilitation.

- **Comprehensiveness**

The technology "imperative" has been used to describe the scientific and applied research over the past couple of decades that have resulted in new, sophisticated and usually expensive diagnostic and therapeutic technologies. Most often this imperative has been associated with the ability to diagnose conditions more accurately and provide a new and sometimes most effective new treatment modality. In some instances the new therapeutic technology provides a "cure," such as a transplanted heart or liver. More commonly, with greater or lesser success, there is amelioration of the destructive biological processes and extend the life span, albeit with a chronic condition such as diabetes mellitus or heart disease.

These therapeutic technologies can range from a new surgical technique (heart-lung transplants), to medical devices (FES for quadriplegia) to new therapeutic agents (cimetidine for gastric ulcers). The pharmaceutical and biotechnology industries have a high investment in research and have enjoyed the world's last completely open market. A study of the development of new drugs, their patenting and marketing is almost an allegory for the U.S. health care system. One drug has recently been approved by the U.S. Food and Drug Administration (FDA) which will benefit at least 75,000 U.S. patients with the chronic illness of kidney failure.

The FDA has approved a highly effective but very expensive drug, epoctin, for the anemia associated with kidney failure that may eventually assist people with anemia caused by cancer, AIDS, rheumatoid arthritis or other diseases. This new treatment is a genetically engineered version of a natural kidney hormone that stimulates the body to produce red blood cells and will become one of the most expensive drugs ever covered under the End Stage Renal Disease (ESRD) program in Medicare. It is likely to cost $200 to $500 million a year to pay for the drug for all beneficiaries of ESRD who now often require transfusions every few weeks for severe anemia.

The drug will be sold under the brand name Epogen and manufactured by a small biotechnology firm, Amgen, Inc. In the U.S., in addition to 75,000 kidney dialysis patients, 20,000 to 50,000 others with less severe disease are expected to be candidates for treatment. The projections of gross income for Amgen Inc. are currently projected at $1 billion a year. Needless to say the cost is attracting wide attention while the company is defending the high price being charged for the drug is an attempt for Amgen to recoup the cost of development which is estimated at $100 million. Others explain that in kidney disease patients, the drug reduces hospital costs by virtually eliminating the need for transfusions. It also appears to be safer than frequent transfusions, which expose patients to infections with blood-borne viruses such as hepatitis and sensitize their immune systems against foreign proteins, making it more difficult for their bodies to accept a kidney transplant.

Even so, U.S. Congressional interest has been stirred to ask the federal agency that manages the Medicare program, the Health Care Financing Administration, "to get a fair price." For some, the new realities of drug pricing are presenting the government with an opportunity to rein in the drug industry. But for the small biotech companies and other pharmaceutical companies that have invested with venture-capital, awaiting approval for complicated and research-intensive new drugs, this sort of delay is a difficult matter. It raises such questions as: Will policymakers (legislative and executive) allow the drug industry the same rates of return it has received over the past 25 years? Will the industry have to make the transition, and can it, from marketplace to managed prices? What signal would it send to the money-markets since this is a long-term capital-intensive business? Can those affected with rare diseases ever expect to see orphan drugs developed?

- **Continuity**

After nearly a decade of pervasive despair, the AIDS epidemic has for the first time entered a phase in which, with aggressive treatment, the disease need no longer be considered an immediate death sentence. Nobody has ever been "cured" of AIDS. And nobody will be any time soon. Treatment is still expensive, complicated and at its best only a relatively short-term palliative. Nonetheless the cumulative evidence is that, for AIDS victims, with proper medical attention and access to an emerging armamentarium of new drugs, many patients once thought to have no hope can live for years.

Despite the apparent good news an irony had evidenced itself in the aggressive stance taken by public health officials seeking to contain the epidemic. The diagnostic tests and preventive treatments are very expensive and nobody seems to have any idea who will pay the bill. Preventive care for any disease is ordinarily less

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expensive than hospitalization, but most health insurance plans in the United States, including government plans, do not recognize this. Insurance plans generally do not pay for experimental drugs, including AZT.

Recently, officials from the U.S. Centers for Disease Control and the National Institutes of Health recommended that many still-healthy people infected with the human immunodeficiency virus (HIV), which causes AIDS, begin taking a drug that appears to prevent a deadly pneumonia.

The drug is aerosol pentamide, which appears safe and effective in preventing the pneumonia that is the leading cause of death among people with AIDS. Costing about $150 each month, however, its expense—especially if any of the 1.5 million infected Americans take it regularly—has caused great concern among those who have to provide health care financing.

Early in the epidemic, there was little more doctors could do for the AIDS patients than make them as comfortable as possible. The entire hope for stopping the spread of the disease lay in teaching people how to keep from becoming infected. Most agree that prevention is still the most important and most effective way to fight AIDS. But as new drugs are developed at least some of the emphasis shifts to medical care.

If there is a widening gap between scientific progress and federal funding priorities, it is largely unavoidable(30). Researchers are working as hard as they can to develop and test new drugs for disease that is expected to affect increasing numbers of Americans over the next several years.

Nobody expects scientists to refrain from recommending a new therapy just because federal officials may not have the money to supply it to everyone who wants the drug. And recent experiments in several areas appear promising enough to create an increased demand for drugs in the coming years. That, in turn, will probably encourage many more people who suspect they are infected to get tested and seek treatment.

But what is probably more remarkable about this "terminal" disease is the continuity of care many receive that is completely unrelated to the formal health care system.

Little is really known about the magnitude or the extent of health care provided by an informal network of family, friends and others. It is often argued that this is the appropriate role for this informal network and any "coverage" in financing has the effect of a "moral hazard."

The notion here is that what simply happens when a service or program is financed, which could be provided by a trained informal care provider, results in a shift to the formal network. The evidence for this phenomena is weak but presumably the sicker the person cared for by the informal provider the more likely this is to happen.

In certain instances it would seem to be wise in the stewardship of limited resources to provide support to this informal network as a cost-avoidance measure. For instance, respite care would seem to ensure the care giver does not "burn out" which might result in earlier institutionalization, usually more costly, of the recipient of their care. This is not a well developed and accepted part of funded services and programs and is but one facet of the need to promote autonomy and functional independence.

The sustaining support needed by those with chronic physical and mental illness is an area that is generally neglected. It is certainly not "glamorous" to only be a carer when a cure cannot be found. Consequently it is not surprising that support, that is financing, of long-term care services have not been resolved in the U.S.

Approaching a Means of "Fairness"

In the U.S. it still seems premature to expect a board agreement on fair-sharing as the previous examples illustrate. There may just be a couple of areas in which agreement might be reached before such agreement can be reached. They are an understanding of *technology measurement* and deciding on a *basic "set" of medical/health services*.

- **Technology management**

The influence of designating Medicare reimbursement for new technology is not a small matter. It is believed that the government's role in pricing has claimed one victim. Calfiornia's Genetech Inc. ran into heavy criticism from the U.S. Congress for the pricing of its heart drug TPA in 1988. HCFA did not allow Medicare to pick up the tab for the $1,200 treatment, contributing in part to the product's disappointing sales. HCFA's procedures for approving coverage for medical services and diagnostic/therapeutic technologies have always been a bit mysterious until it lost a court case. It recently published in the January 20 Federal Register the procedures it will follow. Already it is sparking considerable controversy because cost-effectiveness has become a major factor in the deliberations. HCFA offers the following cost-effectiveness criteria:

1. less costly and at least as effective as an alternative covered technology.

2. more costly than an alternative but more effective, and improved outcomes justified the additional expense.

3. less effective and less costly than an alternative but viable for some patients.

- **Basic "set" of medical/health services**

The American Medical Association over a period of several years convened many panels to define the Health Policy Agenda for the American People(31). This report by a coalition of 172 public and private sector organizations identified Medicaid reform as one of the U.S.'s most urgent health care issues. The most significant role of an Ad Hoc Committee on Medicaid was to make a series of recommendations which, while focusing on improved eligibility, uniformity and effectiveness of the Medicaid program, define a basic "set" of medical/health services(32).

1. The Medicaid program should be restructured so as to be governed by national standards and goals.

2. The categorical line of Medicaid eligibility to public case assistance (welfare) programs should be broken; income eligibility for the program should be set at no less than the federal poverty level.

3. All states should be mandated to adopt a Medically Needy program with "spend down" eligibility provisions. Asset testing should be acceptable as an eligibility requirement only under the Medically Needy provisions. "Medically needy" persons are those whose incomes exceed the Medicaid eligibility level but who have been impoverished by catastrophic medical bills.

4. A standard benefit package should be provided by each state and should be federally mandated. It should include physician services; inpatient and outpatient hospital services; laboratory and roentgenogram services; prescription drugs; institutional care for the elderly and the physically or mentally disabled; dental services; early and periodic screening, diagnosis, and treatment services; family planning services; home health and personal care services; and other medically necessary professional services.

5. Medicaid expansion should include measures to promote cost-effective provision of services.

6. Medicaid expansion should include policies and incentives to encourage broader health care provider participation.

7. A greater burden of the fiscal impact of

> *These are troubling issues which relate to a clear sense of "fairness" in the allocation of resources to disabled citizens. In essence what is probably needed is a better socio-ethical theory to adequately answer these questions.*

eligibility expansion should be borne by the federal government. At the same time, the federal formula governing reimbursement to States should be revised to correct for tax-burden inequities.

8. Long-term care services should be continued under Medicaid or through a structurally improved program.

This approach to specifying a uniform benefit package for the poor may yet have the effect of forcing the clarification of health and medical care for everyone(33).

Impact on the Disability and Rehabilitation

Disability and rehabilitation is almost a topic unto itself except that tradeoffs in the allocation of resources seem to always place those with chronic illnesses and at a disadvantage(34). The need for rehabilitation services grows and decisions are made concerning the allocation of resources for newly rescued patients with new chronic disorders. Specialized programs have concentrated resources on specific populations (e.g., brain and spinal cord injury, stroke, amputees) raising questions of justice and equity. Of course, quality of life issues will probably affect decisions to provide resources. These are troubling issues which relate to a clear sense of "fairness" in the allocation of resources to disabled citizens(35). In essence what is probably needed is a better socio-ethical theory to adequately answer these questions. Some have been advanced that incorporate a balancing act that ensures "fairness" in the equality of opportunity(36), yet even this will have many practical, administrative and implementation issues to be resolved.

Summary and Conclusion

In all this discourse and exploration of the issues there is no profound answer. There are more fundamental societal values in the U.S. that go beyond the mere consideration of the allocation of "scarce" medical resources. Consensus building will continue to be very problematic. Maybe the initial building blocks: concluding how effectiveness is determined and a simultaneous commitment to a basic "set" of medical services, would move the U.S. towards fulfilling the criteria of accessibility, availability, comprehensiveness and continuity of medical and health services.

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Quality Assurance as an Aid to Ethical Decision Making in Disability Management: Lessons from Recent Ethical Issues Involving Disadvantaged Groups in New Zealand

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The year 1988 was a watershed in medical practice in New Zealand. The reports of two judicial inquiries publicized clinical and ethical deficiencies in the delivery of health care to mentally disordered prisoners, particularly those of Maori descent and to women with cervical carcinoma in situ. In addition, the Royal Commission on Social Policy identified women, Maori, and people with disabilities as major disadvantaged groups in New Zealand society, in a four volume report published in 1988 (April Report 1988). This report also identified inequities in the New Zealand benefit system, and stated "there is no justification for the stark difference between the treatment of the sick and disabled (who get generally lower levels of income-tested benefits). As an additional injustice the injured have priority access to health care, compared with the sick and disabled".

Although the inadequacies in service provision revealed by the judicial inquiries had been previously recognized, the publication of the Report of the Cervical Cancer Inquiry (Cartwright, 1988) and the Psychiatric Report (Mason, 1988) resulted in the implementation of management strategies to correct these deficiencies. They therefore fulfilled the requirements of quality assurance whose aim is not only to identify areas of practice which do not reach accepted standards, but to rectify this inadequacy by taking effective steps to improve the quality of service so that appropriate standards may be met. In addition, both inquiries reinforced the need for consumer input in setting and auditing standards of ethical practice. This paper will also include an example of this practice in which people with severe handicap are involved in decisions about the implementation of cardiopulmonary resuscitation should they suddenly collapse while resident in a younger disabled unit.

These principles not only aid decisions involving disadvantaged individuals, but also provide guidelines for resource allocation to people with disabilities, thereby assisting in the resolution of the ethical dispute between the common good and the good of individuals .

The ethical considerations identified by Jonsen et al (1982) are exemplified by the aforementioned disadvantaged groups (Table 1). Following discussion of these ethical issues, this paper will present an ethical philosophy based on respect of persons and resultant commitment to communication which also facilitates the use of quality assurance principles to set ethical standards. These principles not only aid decisions involving disadvantaged individuals, but also provide guidelines for resource allocation to people with disabilities, thereby assisting in the resolution of the ethical dispute between the common good and the good of individuals (ten Have, 1988).

Cervical Cancer Inquiry

The report of the cervical cancer inquiry resulted from the outcry which greeted an article by two New Zealand journalists in a widely read magazine. This reported the results of a scientific paper published in the gynecology

> ***. . .requests were repeatedly ignored by administrators, in part because of the additional costs which would be involved.***

literature in 1984 detailing the poor outcome in a group of women with positive cervical smears treated at the National Womens' Hospital in Auckland, the largest city in New Zealand. The paper (McIndoe et al, 1984) showed significant progression of cervical carcinoma in situ to invasive carcinoma in a group of 130 women with persistently positive cervical smears as a result of deliberate under-treatment compared to a negligible rate in 817 cases who had normal smears after treatment by conventional techniques. Six percent of women in the former group died compared with 0.5 percent in the adequately treated group. This policy of deliberate under-treatment was based on the faulty hypothesis in 1966 that carcinoma in situ did not progress to invasive carcinoma, despite the world view at the time that carcinoma in situ was a precancerous condition. Following an exhaustive inquiry, Judge Cartwright presented her report. This was particularly concerned with the lack of informed consent obtained from any of the patients included in the trial, which was based on the sincere but misguided belief of the gynecologist responsible for the treatment policy, who wanted to save women from unnecessary mutilating surgery. Judge Cartwright was also critical of the lack of attempts to contact women who had been inadequately treated and were still at risk of invasive carcinoma 22 years after the commencement of the trial. She attributed the reasons for the failure to treat adequately carcinoma in situ to a number of factors, including:

- "Failure to recognize the dangers for patients when procedures were adopted which did not comply with generally accepted standards of treatment at that time. .
- Failure to evaluate adequately the risks to patients of the hypothesis on which the 1966 trial was based (that carcinoma in situ is not a pre-malignant disease) was incorrect. .
- Failure to note the rising incidence of invasive cancer among patients included in the trial; and failure to stop the trial and treat the patients as soon as the cogent evidence of this risk began to emerge. .
- Mediocrity of standards in care in some clinical areas and, in particular, in the standard of information offered to patients."

All of these factors might well have been avoided by an adequate quality assurance program.

Public Offenders with Mental Illness

The next example of deficient medical services offered to people with disability relates to public offenders with mental illness. The ethical consideration involving mentally disordered prisoners is that they should at least be given the opportunity to be assessed by a qualified psychiatrist to determine if the indications exist for medical intervention, in order to relieve the suffering of those patients with a mental illness, even if a cure is not possible. Although the New Zealand law is clear on this point, it is apparent that the placement of such prisoners has long been a vexing question. The New Zealand Inspector of Prisons wrote in his annual report to Parliament in 1882 "the question respecting lunatics and inebriates being placed in prisons or hospitals ought to be settled once and for all. It has been for 10 years, a case of each institution refusing to take them in".

Despite numerous working parties over the past decade which recommended that the Auckland Hospital Board provide secure facilities at the local psychiatric hospital, these requests were repeatedly ignored by administrators, in part because of the additional costs which would be involved, which were considered to be national rather than a local responsibility.

However, the gross deficiencies in forensic psychiatry services were highlighted in a further judicial inquiry which was set up in 1987 in response to the public outcry which resulted

If such a philosophy is to be successful, it implies the provision of adequate facilities in the community.

when a mentally disordered patient, who had been in psychiatric institutions for 20 years, was discharged to the community without adequate psychiatric support, and subsequently fatally stabbed a fellow resident of his boarding house, and severely wounded two others, during a psychotic episode. During the inquiry which was chaired by Judge Mason it became apparent that mentally disordered prisoners were not being referred to psychiatric institutions, the admission sin 96 being 149, compared to 414 in 1980. In addition, people of New Zealand's indigenous Maori race, who for approximately 10% of the New Zealand population, were disproportionately over-represented among the mentally disordered people in the forensic psychiatry group, being approximately one third of the admissions admitted to psychiatric hospitals. At the maximum security prison in Auckland, the number of prisoners committing suicide grew from one between 1969 and 1982, to 13 between 1983 and 1987, during the period in which the admission rate to the local psychiatric hospital was falling, despite the perceived need identified by prison staff, whose impressions were confirmed by the independent assessment of a panel of psychiatrists who reviewed the relevant case histories. Among the causes of the increased suicide rate was the apparent policy of the psychiatric hospital which would only admit straight forward cases of mental disorder that would readily respond to a therapeutic regimen. Although Justice Department officers supported the development of greater care in the community for psychiatric patients, they emphasized to the Mason committee that the need for secure facilities for some patients would remain and must be accepted by hospitals.

If such a philosophy is to be successful, it implies the provision of adequate facilities in the community. In his report, Judge Mason identified a number of barriers to good community care, including the:

"lack of adequate funding: there needs to be i) bridging finance which enables the development of community facilities before patients are discharged into the community; and ii) an adequate budget for the ongoing provision for community psychiatric services;. . .

lack of consultation with patient groups; with community groups and with the Maori community in planning and implementation of services;. . .

lack of management structures which would enable the development of initiatives in the incorporation of all participants within the community into these planning structures. . ."

Parallels to Other Groups

It should be noted that the barriers to community care of those disabled by mental disorders is strongly paralleled by similar barriers to those with physical and intellectual disability, and the identification of the lack of consultation with consumer groups is of particular relevance with respect to both ethical and quality assurance principles. The Cartwright and Mason reports illustrate the communication gap which has arisen between providers and recipients of medical services in New Zealand. Campbell (1972) suggests the approach which stresses rational and emotional communication between persons as an ideal in morality is an example of an ethical approach based on respect for persons which places no final authority on moral rules, places the value of the individual above the value of benefit to society, and by a constant attempt to open and maintain communication is the surest sign of trying to benefit the individual person involved. This philosophy is echoed by Walton (1982) who

. . .the lack of consultation with consumer groups is of particular relevance with respect to both ethical and quality assurance principles.

states that "in ethical reasoning about a particular case, there is never any guarantee, but there is always some hope given that each will try to understand the others' arguments".

Quality Assurance

The respect for the other person's point of view and relevance of communication as a means for determining appropriate standards is also of paramount importance in the development of quality assurance programs. Quality assurance has been defined (Shaw, 1986) as "the measurement of provision against expectations, with the declared intention and ability to correct any demonstrated weaknesses". The most important thing, and that which is often neglected, is the putting into place of the management procedures necessary to improve the quality of service to overcome the deficiencies previously identified by systematic evaluation.

Although many clinicians are suspicious of quality assurance as a way for managers to limit resources by means of a utilization review, clinical and social audit, with consumer input, is important if the standards of quality are to be appropriate. Again, communication between managers and clinicians is important for the delivery of quality care. These elements of quality in health services or in individual patient contact have been summarized by Shaw (1986) as follows:

- "**Appropriateness:** the service or procedure is what the population or individual actually needs.
- **Equity:** a fair share for all the population.
- **Accessibility:** services are not compromised by undue limits of time or distance.
- **Effectiveness:** achieving the intended benefit for the individual and for the population.
- **Acceptability:** services are provided to satisfy the reasonable expectations of patients, providers and the community
- **Efficiency:** resources are not wasted on one service or patient to the detriment of another".

Although it is tempting to blame administrators for the reduction of resources for rehabilitation of people with disability, it is important that they are provided with the data to allow them to make rational, informed and ethical decisions.

The demonstration of effectiveness is the task of research, Ostrow (1983) noting that "quality assurance is the interface between clinical research and clinical practice". Ethical decision making can thus be assisted. Johnston and Keith (1983) note that "the most appropriate use of cost-effectiveness analysis is to optimize the allocation of resources and effort between alternatives". Research in the area of cost effectiveness and rehabilitation is sparse, but is well summarized by Ostrow et all (1987) in a book which reviews the validity of both scientific method and the cost effectiveness data in the 20 or so papers devoted to this topic which have appeared in the literature to date. Although it is tempting to blame administrators for the reduction of resources for rehabilitation of people with disability, it is important that they are provided with the data to allow them to make rational, informed and ethical decisions. The Professor of Geriatric Medicine at the University of Manchester has stated: "my starting assumption is that rehabilitation is facing a crisis and that the crisis has its roots not only in central government indifference to the plight of the disabled, but also in the average rehabilitationist's indifference to scientific inquiry" (Tallis, 1988). Once research has produced the necessary information base, policy decisions concerning what services to produce and how to distribute them can be made.

The essence of quality assurance is the comparison of actual care against a pre-established model of "good" care. This model consists of criteria which identify the most important com-

the phrase "quality of life" is highly subjective, it is often used by someone other than the person whose life is being evaluated

ponents of good care, and standards which indicate which level should be reached in each criteria. One of the key tasks in the quality assurance program is to identify the area which it is meaningful to study and then determine by means of consensus the criteria of quality and the standards by which to measure this. The need for quality assurance and the suggested criteria in standards of good care are recommended in all the reports of New Zealand ethical issues which were discussed above. For example, Judge Cartwright in the report of the 1988 cervical cancer inquiry stated the need for treatment protocols, patient information and quality assurance programs, which involved in-hospital and external audit and involvement of the patient. Similarly, Judge Mason recommended the need for internal and external audit of community psychiatric services, and involvement with the community and patients groups in the decision making process.

"Quality of Life"

These criteria have equal relevance to all people disadvantaged by disability, whether it be physical, mental, intellectual or social, and are illustrated by a prospective survey by people classified as "dependent handicapped" who were at potential risk of being denied cardiopulmonary resuscitation (CPR) on the grounds that their perceived quality of life did not warrant active intervention in the case of sudden collapse.

Adults with physical disability are often discussed with respect to their quality of life. Jonsen et al, (1982) pointed out that the phrase "quality of life" is highly subjective, it is often used by someone other than the person whose life is being evaluated, including doctors on the resuscitation team who are young, fit and healthy, according to Petrie (1987) who surveyed 41 people with severe disability who were admitted to the young disabled unit at Waikato Hospital. Over 75 percent of the residents expressed a wish to have CPR. Of the nine patients choosing not to have CPR seven were in the group of 26 over the age of 45 years and eight had been disabled for more than ten years. Five of the eight who did not wish to have CPR and who had completed the Beck depression scale had mild to moderate depression, compared to two of the twelve in the group who wanted CPR. The opportunity to make an informed decision was positively received by all residents.

Royal Commission on Social Policy

The most extensive quality assurance program in New Zealand involved the work of the Royal Commission on Social Policy, who consulted exhaustively with many of New Zealand's three million people, who made over 6,000 submissions as well as taking an active role in formal surveys. The terms of reference were "to receive representations upon, inquire into, investigate, and report on—

(i) The extent to which New Zealand meets the standards of a fair society and the main reasons why New Zealand falls short of any of these standards. The standards of a fair society were considered to be:

- "dignity and self determination for individuals, families, and communities;
- maintenance of a standard of living sufficient to ensure everybody can participate in and have a sense of belonging to the community;
- genuine opportunity for people, of whatever age, race, gender, social and economic position or abilities to develop their own potential;
- a fair distribution of the wealth and resources of New Zealand including access to the resources which contribute to social well-being;
- acceptance of the identity and cultures of different peoples within the community, and understanding and respect for cultural diversity".

> *The criterion which was adopted by the Commission was that all New Zealanders are entitled to social well-being, which was defined as being "recognized by the extent to which all have a reasonable expectation of those things which are generally accepted as necessary for a healthy, happy life". . .*

The criterion which was adopted by the Commission was that all New Zealanders are entitled to social well-being, which was defined as being "recognized by the extent to which all have a reasonable expectation of those things which are generally accepted as necessary for a healthy, happy life", with the standards listed above the value on the criterion that indicate the boundary between acceptable and unacceptable quality of life in a fair society.

Means by which criteria and standards can be developed in the area of services for adults with physical disability are included in the recommendations of the Strategic Planning Guidelines for Area Health Boards (Department of Health, 1989) these include the following:

- "Rehabilitation Services Development Groups (SDG) be set up to establish local needs and current resources, and plan further developments including a management structure to set the services in place and allow them to function. . .
- People with disabilities be involved early in the planning of services by setting up a Service Advisory Committee of consumers. This group will work in partnership with the SDG and advice as services are planned, and then monitor consumer satisfaction. . .
- A Service Audit Mechanism be developed to establish outcome measures and monitor performance by professionals. . .
- Area Health Boards take an inventory of all services available in the local and regional area, publish this in a booklet form and update this every year. . ."

It was recognized that to be assured of quality rehabilitation service, "a manager for Rehabilitation Services should be appointed and ensure that coordination between consumers and service providers takes place".

The means by which rehabilitation service development groups and service advisory committees might work with the assistance of a manger to set standards is suggested by Shaw (1987) as follows:

- "Define the subject. . .
- Research the common wisdom. . .
- Assess local practice. . .
- Reconcile the difference. . .
- Test the guidelines. . .
- Adopt the guidelines as standards".

In summary, both quality assurance and ethics are intimately linked with the rights of the individual and his or her interdependence with society. The task of all of us, as providers and consumers of services, is to work together to determine the criteria and standards which will provide at least the basic requirements of a meaningful life and the outcome measures to monitor the success of interventions which society introduces to achieve these. We are then in a position to negotiate rationally with those responsible for the allocation of funds, in order that these standards may be met in the most cost-effective manner. With the consumers providing input into the factors which will provide them with good quality care, service providers accepting the responsibility to deliver this care, and health economists taking note of these principles, it should be possible to provide the most cost effective means to deliver a high quality of care at an affordable cost. By

> *. . .both quality assurance and ethics are intimately linked with the rights of the individual and his or her interdependence with society.*

Table 1: Recent Ethical Issues in New Zealand

Ethical Considerations	Ethical Principles	Disadvantaged Group
Patient preferences	Autonomy	Women with Cancer
Medical indications	Beneficence	Mentally disordered (Maori) prisoners
Quality of life	Beneficence/utilitarianism	Adults with physical disability
External factors	Utilitarianism	Adults disabled by illness

means of formal monitoring with quality assurance programs dedicated to correcting identified deficiencies, the requirements of ethical decision making and social justice should be achieved.

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Disability and Ethical Issues: A Point of View from the Netherlands

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1.1 How is the disability movement structured in the Netherlands?

Over the course of the years it has become clear to me that we in the Netherlands have developed an exceptional structure of organisations representing the handicapped, patients, psychiatric patients, parents of the mentally handicapped and parents of the physically handicapped. Because this complicated form of organisation has continued to be reasonably effective, it appears to me to be worthwhile to give you a glimpse of how it functions.

The **Clients Union (Clientenbond)** is a lobby group of (former) psychiatric patients, who, in cooperation with the **National Patients Councils (Landelijke Patienten Raden)** for the mental-health sector–therefore patients within institutions of the mental-health sector–supports the interests of its members. Examples: whether to apply electro-shock therapy, access to personal files, arrangements concerning compulsory admission, income-earning positions both within and outside the institutions, the right to work, the cultural input, etc.

The **Federation of Parents' Associations (Federatie Van Ouder Verenigingen)** of the mentally handicapped is a cooperative framework of four associations arising from institutions and formed by parents who have adopted as their point of departure their children's and their own common interest. For example: the quality of services within the institutions, opportunities for home nursing, protected work environments, financial facilities, special education, etc.

The **Dutch Council of the Disabled (Gehandicaptenraad)** is a cooperative framework of 60 organisations of people having a physical disability. This council, along with the organisations representing specific services, seeks to get rid of the barriers which cause some people to be handicapped and also tries to promote the idea that "being different" need not be a negative quality. This is achieved by, for example, focusing on the position in the labour market, financial provisions, the quality of assistance and equipment, integration in the educational sector, access to society and the residential environment, etc.

> *This council, along with the organisations representing specific services, seeks to get rid of the barriers which cause some people to be handicapped and also tries to promote the idea that "being different" need not be a negative quality.*

These organisations all have an interest in the way in which this health-care system meets the needs of their members. They have therefore decided to join forces in the field of health care and have formed the **National Patients/Consumer Platform (Landelijk Patienten/Consumenten Platform).**

In addition to the four organisations, two specifically consumer organisations active in the Netherlands, namely the **Consumer Association (Consumentenbond)** and **Consumer Contact (Konsumenten Kontakt)** form part of the LP/CP in addition to a number of five organisations which are involved in the health care sector because of their particular viewpoint and whose members need not necessarily be chronically ill or handicapped (i.e. Child and Hospital). In addition, other participants in the consultation include the joint elderly associations and the two largest trade union federations. Altogether, the LP/CP represents around 11% of the Dutch population insofar as health-care is concerned.

In addition, a number of organisations which deal with hereditary diseases and/or congenital deformities have organised themselves into the **Association of Co-operating Parents' and Patients Organisations (Verenigde Samenwerkende Ouderen Patienten Organisaties).** The Federation of Parents' Associations and around 30% of the Council of the Disabled, along with a few organisations which are not members of either group, together make up this association. The VSOP is especially concerned with providing information on hereditary conditions, encouraging scientific research and increasing public awareness in general about hereditary diseases.

1.2 What is the position with respect to the decision-making echelons?

It would of course be especially interesting to find out to what extent these organisations have an influence on policy in the Netherlands.

If I begin by discussing the VSOP, I can safely say that their influence is large and is still increasing. The exceedingly thorough and sincere way in which the experiences and opinions of especially the parents of children with inherited and/or congenital disorders has been brought forward in recent years has led to, among other things: a substantial number of centres being set up to provide information on this issue, that much scientific investigation is taking place, that the Minister of Public Health could be corrected through the intervention of the VSOP after the publication of a report on the application of information about hereditariness, that an excellent level of cooperation has been achieved between researchers, physicians, ethicists and the VSOP and that a common front is presented to the government.

All in all it is a powerful organisation with a strong position vis-a-vis the decision-making layers.

Despite the fact that the LP/CP is a relatively young organisation, it nevertheless holds a promising position. The government and the health-care sector view the patients/consumers organisation as an equal negotiating partner in its entirety and believe that it should have at least as much as influence as the providers of the service, the insurers or the government. The LP/CP is "in", received a lot of attention and in any case gets enough money from the government at present to carry out its tasks. In addition to the national platform there are now also provincial and regional platforms. Up until now the LP/CP was more or less responsible for helping to bring about legislation which sets the position of the patient (rights and duties) and for developing a model negotiating agreement between the suppliers of (para-) medical services and patients. In the last two years it was able to prevent medical specialists from fighting their wage dispute with the government over the backs of the patients by means of strikes. The LP/CP challenged the specialists before the courts and won every time.

Especially in Parliament much interest has been shown in the LP/CP, and its influence on the decision-making layers is substantial and is increasing all the time.

Finally, there are the organisations of the disabled and/or their parents, who occupy themselves with all possible fields related to their interests. The withdrawal of the stigma of being handicapped from the charitable sphere–more or less–is of course a victory, but has not made life any easier for those concerned. Nevertheless, this step has proved to be extremely important in bringing about a change in attitudes.

In the Netherlands we must get by without a Civil Rights Act and only have the constitution under which to resolve the various issues. In the case of employment a 5% quota has been enforced for physically disabled persons in all sectors of our society; the accessibility to public buildings in increasing; it is becoming increasingly easier for handicapped children to attend a "normal" school; public transport is becoming more and more accessible; the health services sector is increasingly willing to meet the demands formulated by handicapped persons themselves; and more and more people with a handicap are, thanks to the training activities of the organisations, better able to deal with their own circumstances and take the right steps to deal with this.

The influence on the decision-making layers is less deep but far more widely spread than that of the organisations mentioned earlier, and can most certainly be called substantial and growing thanks to the increasing self-awareness among the disabled and their parents!

2.1 Health on the micro, meso and macro levels.

Health is a very special concept. If you should ask me how do I feel, then my answer would most probably be: Fine! I feel good, certainly not ill, I'm sitting comfortably, the company is pleasant and I am doing something which I find especially pleasant–it is therefore logical that my answer should be "Fine".

My environment however, takes a different view: "Isn't it wonderful that she can still make herself so useful despite everything" or "How stupid of her to carry on so carelessly, when she already has enough difficulties" and words to that effect which suggest that I cannot be regarded as a healthy person, let alone someone who can function in a healthy manner.

Society or the government goes even further by deciding in its wisdom that I am not healthy enough to take part in the normal labour process and therefore have to enjoy the privilege of welfare benefit.

In other words, health is something for society to manipulate, for the environment to dictate and for the individual, well, probably something to emulate!

However different our experiences of our own health may be, our environment and society is arranged in such a way that there are serious consequences attached to the label "unhealthy". And these consequences are in turn of great influence in the way in which we ourselves experience being "unhealthy". In other words, health is not only a certain physical and psychological condition in which a person may find his or herself, but also a collection of sociological and economic determinants. And these determinants are culturally defined so that health in New York is a totally different concept from health in Cairo, for example.

However different our experiences of our own health may be, our environment and society is arranged in such a way that there are serious consequences attached to the label "unhealthy".

Can health then be defined at all? Let us make an attempt.

Let us begin at the **micro level:** one person continues to work normally despite suffering a severe bout of flu, while another stays in bed for a few days. How can you compare these two people and what does this tell us about the concept of health? You can compare them in the sense of noting that health is an individually defined concept. No one can therefore tell you that you are healthy–if one looks long enough one will always find something that is not altogether right. You can only decide for yourself if you *feel* healthy (not that you *are* healthy). How you proceed from here depends especially on your character, education, circumstances and cultural background.

Therefore, on the micro level health cannot be defined.

Surely this should be possible on the **meso level** then? How does my environment determine what is "health": are appearances enough to satisfy the norm, does the person concerned behave like a healthy person, is he not perhaps lazy instead of ill, is his family life in order–in other words all factors which are preferabe, not based on sound information. But the *judgment* is nevertheless swiftly passed, and I have here deliberately used the word judgment because so much depends on this verdict. And if there

> *From an old socialistic dream that society is makeable we have now landed in an individualistic dream or perhaps nightmare that life is makeable. This dream leaves little or no room for "being different".*

is one thing that is defined by culture then it most certainly is those judgments which set the norms for health.

Health is therefore undefinable on the meso level as well, even though we pretend that it is possible.

In any case, definition must be possible on the **macro level,** because this is where health policy is made, from the World Health Organization downwards. And if you make policy you should at least know what your goals are. The Dutch government has chosen for an exclusive definition: *Health is the absence of illness*. You and I know that this is a ludicrous definition, because if a body is healthy this is also because it has undergone illnesses–whether in real form or in the form of vaccinations. Illnesses can make people aware of things which are not functioning properly (stress, poisoned food, etc.) or equip people in order to deal better with illnesses or discomfort in the future. In other words, illness is a part of life! Nevertheless, government policy is aimed at preventing illnesses–*at least insofar as this is economically feasible.* This policy is brought about by means of providing information, screening, vaccination, scientific research and medical treatment. In addition, a proper health policy is also contributed to by means of safety measures, peace, economic stability, proper housing facilities and a sound environmental policy. But the government also uses its definition of health to exclude people or otherwise manipulate them. The process of medicalisation is a good example of this, as is the difficult access for the "non-healthy" to the labour market.

2.2 Is there any choice?

What freedom do people therefore have to do with their health, their lives as they see fit? And does the increasing knowledge and the development of various new techniques make such a choice possible?

It is debatable whether a social consensus will ever arise around the ethical dilemmas with which we are confronted because of the rapid developments in the natural sciences. For the first time in the history of mankind it is possible to influence **the form of life:** fundamental involvement both before conception and during pregnancy as well as in the later stages of life is now possible by means of manipulation or replacement. This technical ability must be seen against the background of current medical practices. This medical practice is based on two pillars, namely epidemiology and the urge to treat, to execute a therapy. On the basis of epidemiology it is determined what should be considered as "defective" and current medical training ensures that a doctor will want to treat such defects. This, added to the government view that health is an absence of illness, opens a new Pandora's box. It would appear that just about everyone has been dragged along into the "eternal life syndrome" and the drive for "perfection". From an old socialistic dream that *society* is makeable we have now landed in an individualistic dream or perhaps nightmare that *life* is makeable. This dream leaves little or no room for "being different". And because "being different" is the basic point of departure of an organisation such as the Dutch Council of the Disabled, we now experience serious problems.

In the Netherlands there are more and more people who choose to no longer have their illnesses or defect treated. This applies both to life-threatening sicknesses and to incapacitating illnesses. This happens for various reasons: the treatment is sometimes worse than the ailment, treatment does not produce the desired results, the treatment focuses one on the illness and not on one's life, no confidence in medical knowledge, etc. Running parallel to this development is the application of euthanasia techniques, an issue which was the subject of a fierce debate in our Parliament this spring.

> *Can one person decide for another whether the quality of his or her life is adequate? No, but it nevertheless does happen and it is uncertain which criteria play a role. Parents decide for their children, children decide for their aged parents, doctors decide for their patients and the government decides for its citizens.*

These two developments recently found a tragic overlap: after consultation with the parents a team of doctors decided not to operate on the ileus of a newborn infant born with Down syndrome, so that the baby died within the next 48 hours. Motivation: the quality of life of a "mongol baby" is so poor that it is not worth the effort of helping him overcome such a simple defect at birth. This decision led to tremendous upheaval and is now the subject of a judicial and ethical inquiry.

The key concept to this debate is clear: *the quality of life*. Can one person decide for another whether the quality of his or her life is adequate? No, but it nevertheless does happen and it is uncertain which criteria play a role. Parents decide for their children, children decide for their aged parents, doctors decide for their patients and the government decides for its citizens.

It is in this evaluation process, the identification of criteria of how to approach and handle the concept of a quality of life, that organisations representing people with a handicap should play a crucial role. They can contribute crucial issues drawn from their own experiences to the debate, throw light on the quality of "being different" and provide living proof of quality despite, or perhaps because of, their limitations.

2.3 Applying knowledge of hereditariness as a choice

How can we deal with the new knowledge? What role should it play in our decision-making?

One thing is certain: more and more information is being provided on the physiological basis of our lives, the DNA information. Given the background to my story it is not amazing that I am a proponent of the need to follow this development with great interest and caution.

If everything develops according to the expected trends then we will soon know a great deal about the expected defects, the cause or origin of sicknesses and defects, and about the susceptibility some people have to certain types of sicknesses and defects.

For that matter we know nothing more about the extent to which people are capable of dealing with life–and therefore also its illnesses, traumas and grief.

As an individual you can use this information in two ways:

a) with preventative intentions by, for example, living your life in such a way that you avoid the slightest chance of activating your susceptibility to a certain illness, by means of dealing with the cause of the illnesses or finally by avoiding a life in which illnesses and defects can be expected;

b) as information to equip yourself against that which can be foreseen, so enabling you to take the right measures at an early stage to begin an adequate treatment and start developing that part of the body and personality which will not be changed by the susceptibility and to train the part which will be changed in such a way that it can deal with the defect.

At the societal level, decisions will be taken which will also be based on this information. I will try to illustrate this with a number of examples.

a) The government says it supports the ability of its citizens to choose in freedom, but at the same time takes such measures that the level of health care drops, so that it becomes especially "unattractive" for parents to allow a child with a handicap to be born.

b) Insurance companies will base their

tariffs on hereditary information. This could lead to people with a poor life-expectancy diagnosis paying a relatively lower tariff for health insurance and a high tariff for life insurance.

c) In dividing up the funds in the health-care sector, someone with a favourable prognosis will be more eligible for life-increasing or quality-improving treatment than someone not expected to live much longer: he would be a bad investment.

d) Companies will try to put the right people in the right jobs: you will fit people according to the place of employment, instead of adjusting the place of employment to the needs of the people.

e) Labour disability benefits are refused, for example because someone has not done everything in his or her power to avoid the cause of the disability or to treat it in time.

Nevertheless, I must note with some bitterness that I, as a person with a handicap, have arrived in a position in which I must be able to demonstrate the quality of my own existence in order to make this life attractive as an option for others.

In this summary I have for the time being not considered that some people could be so modified by means of genetic engineering or manipulation that they would be better suited to certain conditions. People have tried to convince me that this is not possible at present and most probably will never even be considered desirable. I have my doubts but nevertheless wish to restrict myself to the realities–as far as I know them.

How people's direct environment will react to individual specific choices can already be noticed. In our society the number of children born with Down Syndrome is declining rapidly. And if such a child is born after all, few people will hesitate before asking whether amniocentesis was carried out–in other words: "Surely this was something you could and should have prevented".

Very cautiously a movement is being created in the Netherlands which is critical of the developments described above and insights are beginning to be created into the possible consequences of any application of the acquired knowledge. I suspect that the organisations representing handicapped people will play a leading role in this because this is where the experience lies in enduring a disabling illness or handicap. Meetings such as the one today will act as a catalyst in this process.

Nevertheless, I must note with some bitterness that I, as a person with a handicap, have arrived in a position in which I must be able to demonstrate the quality of my own existence in order to make this life attractive as an option for others.

3. What's going on in Europe?

The organising committee has asked me to give you some insight into the way in which technological developments are dealt with in Europe. In this it has set a difficult task for me because on the one hand I am not sufficiently aware of what is happening scientifically in this field and on the other because there is little information on what the various organisations in Europe of handicapped persons think about all this. This last point is not so surprising if only you look at the reactions in your own environments to the developments surrounding hereditariness. And let us be honest: very many people with a handicap themselves suffer serious dilemmas when they have to take a decision over a possible new generation or the application of new technologies. And there is also a marked difference in the way that the parents of disabled children respond and the way disabled people themselves respond. Parents are, in general, inclined to spend a great deal of energy in searching for the right treatment, they often desperately look for the cause and sooner have the tendency to ensure that such handicaps do not occur again. Disabled people themselves in general tend to think of this with a greater degree of nuance. Of course,

By way of conclusion I can note the average citizen is barely concerned with the technological developments and that there is no question of social consensus.

among the disabled there is the category which is also continually searching for the ultimate treatment, but there is also a large group which has been able to give the handicap its own place in their lives and are less or not at all involved or interested in treatment. For so far as I know this is something that you will find across Europe. Strong parents' organisations with good contacts in the scientific world and the more divided organisations of disabled persons which each view the issues from their own perspectives.

As I indicated earlier, a movement is slowly developing in the Netherlands which adopts the "crippled is beautiful" philosophy in their attitudes towards technological developments. But these sorts of movements are still so new that they are barely noticeable, not only in the Netherlands but also, I believe, in other European countries. This on top of the fact that in the Netherlands the movement of disabled persons is especially well organised, in contrast to most other European countries, with the exception of Sweden, Norway and Finland.

On the other hand each is taking place in this area in West Germany. For so far as I have been able to make out the vanguard of this movement is a group of women who, aware of the experiences of the Hitler era, have strongly resisted the registration of all sorts of personal data, including hereditary information. And a number of militant handicapped persons have on several occasions disrupted meetings at which matters such as euthanasia, quality of life and abortion due to defects were discussed. So far as I know there is also strong resistance in Sweden against abortion in the cases of defects and against the application of euthanasia. But neither in West Germany nor in Sweden is there any evidence of a policy on these sorts of issues conducted by the organisations of handicapped persons.

Some developments have taken place on the European Community level. On December 19th, 1988 and on January 30th, 1989 discussions were held in the European Parliament on the ethical and legal problems related to genetic manipulation and a disposition to approve a specific research program in the field of health care: predictive medicine, analysis of the human genome and artificial in vivo and in vitro fertilisation. The documentation of these sessions dealing with ethical and legal problems in relation to genetic manipulation is exceptionally interesting but unfortunately too wide-ranging to summarize in the context of this lecture. I have brought a number of copies of this document with me and those who are interested are free to obtain one.

There is much at stake, namely our inheritance and that is something more than simply old castles, hieroglyphics, the Bible and democracy–it is the inheritance of life itself.

4. And in the end. . .

By way of conclusion I can note the average citizen is barely concerned with the technological developments and that there is no question of social consensus.

Science and politics have until now been exceptionally successful in keeping these developments under wraps and the matter has therefore become urgent. However, the Dutch government intends to organise a national round of talks on these issues. I fervently hope that they will do this in close cooperation with the movements of the disabled and their parents and that other European countries will be able to derive lessons from the way this process will develop.

There is much at stake, namely our inheritance and that is something more than simply old castles, hieroglyphics, the Bible and democracy–it is the inheritance of life itself.

Who Shall Live or How Shall They Live? Consumer and Professional Perspectives on Treatment/Non-Treatment Decisions

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Biomedical Ethics, the Consumer and the Rehabilitation Professional

Conventional analysis of the ethical implications of medical technology has focused on technology as an expression of the mastery by medicine over the processes of life and death. Medical ethicists have debated the right of the consumer to discontinue life support relative to the obligation of the health professional to preserve life and prevent death. We are concerned in this paper with the way in which this debate is being framed by the clinicians and bioethicists, ignoring the voice of the consumer, particularly the voice of the disabled consumer. The paper will focus on the criticisms that the latter group have made of clinicians and ethicists for their lack of an awareness of the historical context of treatment or non-treatment decision making. They also complain that the economic realities, including the provision of independent living options, which should be an important dimension of the debate over life support technology, have been ignored by clinicians and ethicists. Finally, in discussing the involvement of the medical professional in the transition from passive to active euthanasia, this paper will review the attendant social and political risks from the same critical perspective as the disabled consumer.

Hastings Center Report

All participants in the Ethical Issues in Disability and Rehabilitation symposium in Denver were given copies of a Hastings Center Report entitled *Ethical and Policy Issues in Rehabilitation Medicine**. In this report, Caplan, Callahan and Hass (Caplan et al. 1987) try to address a wide range of the moral and policy issues which arise within the context of rehabilitation. In this paper, we have used this report to examine contemporary professional values governing consent decisions, truth telling, paternalism and equity in rehabilitation and long term support. We will argue that the representation of the role of the professional expert by Caplan et al. (1987) reflects the traditional preoccupation of both bioethicists and clinicians with decision-making at the level of the individual physician-patient relationship.

Most importantly, many professionally engaged in this debate, whether as ethicists or specialists in rehabilitation, have ignored the fact that technology has also made it possible to provide a higher quality of life for people on life support systems, but that the resources necessary to achieve this goal are under threat.

We will also suggest that the report not only reinforces the dominant role of the clinician in ethical decisions, but focuses on the allocation of scarce medical resources to maintain life, ignoring many of the economic and sociopolitical issues involved in sustaining the quality of that life. Caplan et al., (1987) consider the problems of balancing the rights of the individual against the rights of society in decisions to extend or withdraw treatment; however, in considering the ethical and policy issues involved in resource allocation for community care, they give responsibility for decisions to the rehabilitation professional rather than the individual consumer.

**Reprinted in full in section four of this report.*

> *Our perspective on the potential conflict between professional and consumer control of life support technology has been framed by experience in research and advocacy work with people who have depended on mechanical ventilation since the polio epidemics of the 1940's and 1950's.*

In the third section of our paper we will examine the prospects for demedicalization and will review some of the dilemmas involved in increasing consumer control over decisions about life support. We will suggest that by focusing debate on whether the individual consumer should be allowed to control life sustaining treatment, attention has been distracted from other issues. Most importantly, many professionally engaged in this debate, whether as ethicists or specialists in rehabilitation, have ignored the fact that technology has also made it possible to provide a higher quality of life for people on life support systems, but that the resources necessary to achieve this goal are under threat.

Our overriding concern in this paper is with the interface between individual rights and professional control of technology and resources. We will argue that when rehabilitation ethicists discuss the "right to die", they should also engage the right of the consumer to the means necessary for life, when the quality of that life depends on the availability of technology and a wide array of personal care services. Furthermore, debates over resource allocation should move beyond professional and administratively defined policy considerations in the allocation of resources, but should deal with the rights of consumers to articulate their priorities for resource use.

Research Framework

Our perspective on the potential conflict between professional and consumer control of life support technology has been framed by experience in research and advocacy work with people who have depended on mechanical ventilation since the polio epidemics of the 1940's and 1950's. In the final sections of this paper we will present a brief case study describing the experience of Canadian consumers in negotiating the reorganization of a home respiratory care program (Locker and Kaufert, 1988; Kaufert and Locker 1989). Ventilator users in Manitoba are currently demanding an expansion in the technological support and personal care services which enable them to continue living within the community. These consumers have argued that the ethics involved in long term life support must extend beyond the decision to accept or discontinue treatment. They have asserted their rights to be involved in decisions about the distribution of scarce resources. They have argued for the right of the impaired person to live outside institutional controls. They have insisted on the responsibility of the policy-maker to incorporate consumer, as well as professional expertise into the decision-making process.

> *. . .consumers are being given the right to discontinue life support, but are not being provided with the resources to create quality, self-directed life within the community.*

Since the conference, we have added a postscript to the original paper in which we discuss some of the statements made by consumer advocates speaking at this conference. Their concern, as it was also our concern in this paper, was that consumers are being given the right to discontinue life support, but are not being provided with the resources to create quality, self-directed life within the community.

Professional and Consumer Perspectives on Quality of Life Assessment and Discontinuation of Treatment

Bio-ethicists have acknowledged disability as a consideration in their arguments since they

. . .the evolution of ethical principles within rehabilitation medicine owes more to the perspective of the health professional than the consumer rights advocate.

have become involved in ethical questions arising from decisions to maintain or discontinue life supports. The classic example has become the decision to place (or maintain) a chronically impaired patient on a ventilator against their wish to discontinue life support. The debate has focused on the question of who should control this life and who should make the decision to turn off the system.

"Whose Life Is It?"

This dilemma has been dramatized in stage, film and television programs, most notably in the play and film, "Whose Life is it Anyway?". The subject was the different responses made by care-givers to the demands of a disabled patient that life-sustaining treatment should be discontinued. The initial refusal of the health professionals involved is couched in terms of an assertion of their medical authority and expertise. They also argue that the competence of the patient to make informed decisions is diminished during the initial period of post traumatic stress. The crux of the drama turns on the patient seeking legal counsel, which leads into a legal decision that the patient is "competent" to evaluate the implications of his/her decision and that they want to make this decision while they are competent and in control of their treatment situation. By focusing on the decision between life or death, this particular drama conveniently assumes that the very negative prediction which the patient makes relative to the quality of life experience on ventilator support is valid. The probability is that the patient making the final decision has insufficient knowledge about the course of the illness and alternative approaches to living with life-support systems in the community. The authority of the medical expert is emphasized, but not the potential role of the health care and rehabilitation professional in providing and prioritizing information. Indeed, neither the clinicians in this drama nor the patient appear to give much detailed consideration to alternatives to institutional care. Any discussion of the resources which may be required to sustain a "quality" existence, as distinguished from the minimal medical and technical support required to sustain life, is notably lacking.

This particular drama is the best known, but the ethics literature thrives on case studies and includes many parallel examples. The problem with most of these case studies is that they 'decontextualize' decision making by stripping away the social context. Consideration of the resource commitments necessary to provide an achievable quality of life are ignored. These case studies describe the various actors involved in a decision, but the presence of individuals who actually live on life support systems is rare. The disabled consumer rights advocate does not wheel into these dramas to serve as a peer counsellor, speaking to the potential quality of life achievable from their personal experience of actually living with a life support system.

We suggest that the approach to decision-making portrayed in dramas, such as "Whose Life is it Anyway", combines the lay stereotype of life lived on a support with the model of the dependent patient offered by the rehabilitation professional. It is based on their view of proper provider/patient relationships rather than the alternative vision offered by the consumer advocate. In the next section, we will examine how the evolution of ethical principles within rehabilitation medicine owes more to the perspective of the health professional than the consumer rights advocate.

Ethical Issues in Medical Rehabilitation

A detailed examination of the Hastings Center Report reveals the sources of current interest among rehabilitation professionals in treatment or non-treatment decision-making involving chronically impaired individuals. Caplan et al. (1987) emphasize that interest in ethical decisions within the field of rehabilitation is relatively new. They contrast the ethical decisions made in acute care with those to be made in rehabilitation medicine:

> *It is clear then that medical rehabilitation differs in many respects from emergency or acute care. It is also clear that interest in unique ethical issues of rehabilitation is on the rise. It is therefore essential that both bioethicists and those who deliver or receive rehabilitation services identify the salient moral dilemmas and determine whether ethical analysis based on emergency or acute care paradigms are adequate. (Caplan et al. 1987, p. 3)*

Discussion of the underrepresentation of case examples from rehabilitation medicine in the ethics literature, Caplan et al. (1987) describe the emergence of rehabilitation as a multi-disciplinary specialty. They suggest that because of its focus on chronic illness and impairment, ethicists saw rehabilitation medicine as an area which lacked the excitement of other specialties, such as neonatology or emergency medicine. They preferred the combination of high technology and "heroic" medical interventions in life and death situations, seeing such cases as the ideal subject matter for a micro level analysis of the application of moral principles (Caplan, et al. 1987). Case studies of chronic and disabled patients are missing in the ethical literature because of this preference for the simple and the dramatic.

The bio-ethicist is ill at ease with a situation in which the individual patient is engaged in a series of relationships with a series of professional care-givers. Yet, these relationships may hold even more potential for professional dominance and paternalism.

Caplan et al., suggest in the Hastings Center report that another reason for the under-representation of cases from rehabilitation medicine in the biomedical ethics literature lies in the multi-disciplinary character of this specialty. Rehabilitation necessitates the presence of clinicians from several disciplines, each with alternative definitions of their roles and obligations. The presence of multiple decision-makers complicates the situation. Bio-ethicists prefer case studies in which they can concentrate on the relationship between the individual patient and the individual physician, not multiple physicians or rehabilitation experts. Rather than a single code for a single physician, rehabilitation medicine requires a set of codes for a multidisciplinary team of practitioners. The bio-ethicist is ill at ease with a situation in which the individual patient is engaged in a series of relationships with a series of professional care-givers. Yet, these relationships may hold even more potential for professional dominance and paternalism.

Informed Consent in the Rehabilitation Provider/Client Relationship

Alternative models of the provider/client relationship are explored in the Hastings Center Report as Caplan et al., (1987) try to identify the ethical and moral premises of decision making in rehabilitation. They suggest that certain basic assumptions about information sharing and co-participation influence the way in which treatment/non-treatment decisions are made. The ethics and dynamics of power and control in three models of provider/patient relationship are examined. The "traditional" model emphasizes a paternalistic structure in which clinicians make primary decisions in the patient's "best interest"; the physician decides on what information the patient "needs to know". A second, more egalitarian, approach is labelled the "contractual" model; clinicians are responsible for providing care under a contract agreed by both patient and clinician. The third model, the "educational" model, is proposed by Caplan et al. (1987) who see it as more sensitive to the "evolving" capability of the recently impaired person (Caplan et al. 1987:11). By their argument, the "educational model" is more appropriate for guiding ethical decision-making in rehabilitation, partly because it gives the providers leeway to function in a more paternalistic capacity during the initial stages of care. They justify infringements on patient anatomy during the early stages of rehabilitation "in order to insure that subsequent choices are truly reflective of informed voluntary deliberation." (Caplan et al. 1987:11)

Traditional Power Relationships

Although Caplan et al., acknowledge the problems of applying models developed within acute care medicine to the situations encountered within rehabilitation medicine, their approach to the negotiation of informed consent is based on support for relatively traditional power relationships. The educational model is based on the expectation that information sharing and joint decision-making during the early phases of the impairment must be subordinated. Power is concentrated in the hands of the rehabilitation professional, who will control initial decisions-making. In this model, rehabilitation specialists are portrayed as experts, the possessors of long range knowledge about the progression of illness and impairment.

The Report acknowledges that successful application of the educational model will require the establishment of mechanisms to monitor the capacity of the client to make autonomous choices. The rights of the patient to refuse treatment are acknowledged. Caplan et al., state that:

> *Patients may, if they choose, reject care that is known to be beneficial as long as such refusals are based upon voluntary informed choice (Caplan et al., 1987:7).*

Despite these qualifications, the problems of providing patients with sufficient information on the long term risks, benefits or consequences of treatment or non-treatment are emphasized. Rather than advocating a sharing of complete information and a co-participatory relationship, Caplan et al., (1987) justify an initial control of information by the rehabilitation professional, citing his/her possession of unique knowledge about the progression of a disabling condition. They write:

> *Many professionals in rehabilitation would readily acknowledge the priority that ought to be accorded the principle of respect for patients autonomy. But their clinical experience with patients who suffered severe disability, injury or disease makes them skeptical about the ability patients possess to make informed, deliberate and reasoned choices concerning risks and benefits of treatment (Caplan et al., 1987:7).*

Inherent Risks

The limitations of the educational model when applied to decision on the termination of treatment are examined in later sections of the report. Caplan et al., acknowledge the risks and potential for medicalization inherent in the model; however, they argue that power and coercion are essential elements in the therapeutic process. They state:

> *The capacity for free, voluntary choices may have to be facilitated in patients since it may be unrealistic to expect such capacities to be present in those who have suffered grievous and irreversible impairments. The challenge facing medical professionals in rehabilitation is frequently not how to respect autonomy, or whether to obtain informed consent at every stage in the rehabilitative process but, rather, what steps and activities, and with what degree of persuasion or even coercion are morally permissible in the hope of restoring autonomy (Caplan et al., 1987:11)*

While the risk of professional control is acknowledged, Caplan et al. (1987) focus on the ability of the expert to guide the consumer/patient into making the "right" decisions. "Rightness" is defined by the rehabilitation specialist. Caplan et al. justify physician control over decisionmaking in the following terms:

> *The subjective judgments of team members about the ability of a patient to cope with impairments outside the rehabilitation setting strongly influence the kinds of assessments made about the rate of progress of the patient (Caplan et al., 1987:13).*

Most decisions to discontinue care in rehabilitation do not involve direct withdrawal of life support systems, but deal rather with the discharge and referral of a patient from a rehabilitation unit to another setting.

Decisions to Discontinue Care

The final sections of the report conclude with a critical examination of the implications of an educational model with its emphasis an "evolving relationship between providers and patients". The authors recognize the problems of professional control over the assessment of client levels of competence and the dilemmas of discontinuing active rehabilitation. Most decisions to discontinue care in rehabilitation do not involve direct withdrawal of life support systems, but deal rather with the discharge and referral of a patient from a rehabilitation unit to another setting (Caplan et al., 1987). Such decisions are usually initiated by the professional and frequently are precipitated by resource constraints rather than some evolution in the physician/client relationship.

Caplan et al. (1987) acknowledge that the educational model gives the rehabilitation professional a great deal of discretion early in the course of illness. They suggest that this discretion is complemented by a duty to actively involve family members and patients in decisions to end care. Yet, while recognizing the importance and value of increased involvement by patients and family members, Caplan et al., (1987) emphasize that the systematic collection and documentation of information concerning patient progress and plateauing remains the primary responsibility of the professional.

Interviews Illustrating Current Models

The existence of both the paternalistic and the educational model in rehabilitation medicine is undisputed. Reviewing material from our interviews with ten respirator dependent individuals with post-polio respiratory impairment, we found that most of them had experienced one or both of these models in their relationships with clinicians (Locker and Kaufert, 1988; Kaufert and Locker, 1989). They recalled how clinicians had "guarded" and selectively revealed diagnostic and treatment information during the initial period of their dependence upon iron lungs and rocking beds. Many described how they had taken the initiative, asserting a level of independence by obtaining information about alternative community living options, such as respiratory home care programs, or researching the availability of alternative types of ventilators. More recently, those who were experiencing the late effects of poliomyelitis (which further reduced their respiratory capacity and functional ability) reported that clinicians had initiated discussion about the necessity for future re-institutionalization. Most were critical of the continued application of an "educational model"; they argued that medical control was still being exercised by clinicians whose claim over the right to interpret the trajectory of their illness was exclusive and who still controlled the medical, social and economic resources required for community care. For Caplan et al. (1987), however, such paternalism is justified on the basis of prior clinical experience. They state:

> *Moreover a greater latitude in physician paternalism seems justified when physicians and other health providers know from previous clinical experience that a process of accommodation and acceptance is necessary in order to allow patients to come to grips with the reality of irreversible impairments (Caplan et al., 1987:9).*

Demedicalizing Treatment/ Non-Treatment Decisions

In the face of arguments supporting continuing direct and indirect professional control over decisions to continue or withdraw life support, some medical ethicists have suggested that cessation of treatment decisions should be demedicalized. In his address at the 1989 Polio

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and Independent Living Conference, Dr. Daniel Wikler noted a trend towards decisions related to the continuation of life support for patients on long term mechanical ventilation being controlled by consumers rather than professionals (Wikler, 1989). According to Wikler, this demedicalization of decisions to discontinue treatment or withdraw life support systems has been influenced by changes in four areas:

- Changes in technology making available effective life support systems which are more directly controlled by the consumer in the home;
- Changes in societal expectations about professional control of technology developing out of the 1960's cultural revolution;
- The emergence of the consumer rights and independent living movements which have emphasized co-participation and information-sharing in professional/client relationships; and
- Legal precedents asserting patient-oriented, rather than physician-oriented criteria for informed consent decisions.

Wikler argued that these contextual factors had created an environment in which physicians were increasingly comfortable with allowing clients and families to make decisions about discontinuing treatment. His analysis of this demedicalization process does not deal adequately, however, with issues of continued indirect control of decision-making. Professionals exercise this control because they define the range of alternative treatment options and predict the future quality of life.

Rehabilitation Ethics and Resource Allocation

Any examination of consumer and professional perspectives on treatment/non-treatment decisions must consider the impact of resource constraints and policy consideration. Ethicists tend to focus on isolated micro-level issues in the individual clinician/patient relationship and ignore the macro-level constraints in the economic political context of care. Clinicians, however, are showing a growing interest in macro level ethical issues because of the implications for the allocation of resources and control over programs. Caplan et al. (1987) acknowledge the linkage between professional interest in macro ethics and control of resource allocation. They state:

> *In part the sudden spate of interest in rehabilitation ethics is a response to increasing pressures to contain costs. Discussions about the desirability of introducing some form of prospective payment or capitation-based financing into rehabilitation have encouraged professionals in the field to examine seriously their moral obligations to both their patients and to society (Caplan et al., 1987:3).*

This statement reflects the particular policy constraints which are the product of the system of financing health and social services for disabled people in the United States. However, Canadian and European rehabilitation professionals have showed similar interest in influencing resource allocation policy in treatment/non-treatment decisions.

Ethicists tend to focus on isolated micro-level issues in the individual clinician/patient relationship and ignore the macro-level constraints in the economic political context of care.

The extension of the professional expertise into macro ethics and policy formation occurs as the clinician is asked to examine the level of support which is necessary to maintain a person with a given impairment in a specified care setting. Caplan et al. point out that professionals have been led into examining:

> *. . .the level of support that ought to be made available for those seeking rehabilitation services. In attempting to decide the level of support that society ought to provide, it is necessary to understand the nature of the aims and goals that provider and patients bring to this phase of care. In large measure social consensus as to the desirability and feasibility of attaining goals set by those who provide rehabilitation determine the availability of public reimbursement for this type of care (Caplan et al., 1987).*

This passage suggests that the technical expertise to determine who can benefit from particular kinds of care is, or may become, largely the prerogative of the health professional. It is his/her expertise, his/her notion of benefit, which is to guide the allocation of scarce resources. The right to a "quality of life", as defined by the consumer is subordinated to the notion of "benefit" as defined by the technical expert. For representatives of the independent living movement represented at this meeting, the challenge will be to develop policy forums and mechanisms for decision-making which represent the expertise and power of the disabled consumer more equitably.

The right to a "quality of life", as defined by the consumer is subordinated to the notion of "benefit" as defined by the technical expert.

Ethics and Resources: A Case Study

In closing we will use a case study in which we are currently involved (as researchers and advocates) to illustrate the potential conflicts in consumer and professional perspectives on continuation of community-based respiratory care. The case involves the past and present experiences of a group of individuals who developed poliomyelitis during the epidemics of the 1950's and who continue to use mechanical ventilators and personal care services. The majority have been living independently in the community since the late fifties or early sixties. Ventilator users in Manitoba, Canada, are engaged currently in a major policy debate with clinicians and policy makers over their entitlement to resources for 24 hour support in the community. The provincial government has proposed the development of a more unified, centrally administered respiratory home care program. If this model is adopted, the more informal, community-based support system, which has been developed over the past three decades, may be compromised. Consumers see their ability to maintain consumer-directed services, and even to live independently in the community, as under threat.

Policy Development

In developing a more systematic policy for entitlement for respiratory home care, the government has asked medical specialists to work with health policy-makers to develop a series of criteria for determining eligibility. These criteria will be used to create a set of categories, based on levels of impairment and long term survival prospects. Consumer representatives argue that there is a risk of policy change in the level of disability defined as qualifying for program support and access to the option of community-based living. Several consumers have expressed their fears that people with more extensive levels of functional limitation and greater care requirements would be forced to live in institutional settings or 'Fokus' units.

Possibility of Re-Medicalization

Seen from the perspective of these consumers, this plan threatens them with a form of re-medicalization. The provincial government is perceived as establishing mechanisms through which professional control over community care options will be vastly increased. Medical control will be exercised through the right of the professional to predict the probable course of impairment, to define the range of

Decisions over the allocation of the economic and social resources necessary to sustain quality of life and independent living are not morally neutral.

treatment options available, and to authorize what resources are needed. Taken in combination, each of these potential sources of power and control has major implications for re-medicalization or the extension of professional control over the resources and opportunities for independent living required for self-directed care. This situation does not fit the case scenario of the usual cessation of treatment decision. Yet, the themes of control over information and the allocation of scarce resources are very similar.

Conclusion

In summary we would emphasize that the ethical dimension of treatment/non-treatment decisions is very different when one moves out of acute care medicine and into the lives of those requiring long term care and technological support. Community care decisions are less clear cut, but they are also less visible. From the point of view of an ethicist, they lack the drama and clear choice points associated with turning off a life support system. Yet, for consumers faced with the loss of independence and re-institutionalization, the withdrawal of technological supports may be critical not to survival per se, but to meaningful survival as determined by the quality of their lives.

Ethical Dimensions of Decisions

Long term support decisions may be considered within the framework of a micro-ethical debate over the reciprocal right and duties of client and professional and their engagement in an egalitarian and co-participatory relationship. We would argue for the necessity of a macro-level analysis in which clinical and policy level decisions are clearly recognized as containing an ethical dimension. Decisions over the allocation of the economic and social resources necessary to sustain quality of life and independent living are not morally neutral. Proposals to formalize the role of the professional in ethical decisions at the micro level may diminish the prospects for consumer advocacy and peer counselling. Focus upon the provider/client relationship as the sole forum for decision-making may take these decisions out of the political arena in which disabled consumer groups had become effective lobbyists for their own rights. Instead, the shift back to the individual provider/client relationship risks the re-introduction of an individually based framework of action. While we may be acquiring the right to determine when we will die, both the impaired and temporarily able-bodied people may risk losing the right to determine how we will live independently with dignity.

A Postscript

Changes in the medical role in cessation of treatment decisions are closely associated with the issue of professional involvement in euthanasia. Consumer representatives at the 1989 Polio and Independent Living Conference and at this symposium have taken strong exception to the prospect of the role of the professional being transformed from that of "defender of life" to that of "facilitator" in the withdrawal of support systems. Several speakers at the post polio conference emphasized that redefining professional roles and values governing treatment/non-treatment presented medicine with a "slippery slope" leading from passive to active euthanasia. Speakers in Denver, including Hugh Gallagher, have pointed out the risks which arise when the passive involvement of clinicians further changes from the role of facilitator to more active forms of intervention. Fears were expressed that this form of active euthanasia may be more likely in the case of an individual with a chronic but stable condition, who depends upon life support systems. Spokespersons for European disabled consumer groups, including Theresia Degener and Yolan Koster-Dreese (Degener 1989; Koster-Dreese, 1989), criticized the current involvement of health professionals in active euthanasia. Gallagher and Degener described the historical linkages between an emergent neo-eugenics movement and Nazi Germany's Aktion T-4 program (Gallagher, 1989). Other speakers alluded to both historical and contemporary examples of constraints on the autonomy of disabled people in decision-making involving continuation or cessation of treatment. Several established a link between social and political constraints on consumer-directed decision-making and societal attitudes towards the rights of disabled people. As an extension of this form of thinking, a recent letter from Yolan Koster-Dreese emphasized that biomedical ethicists are creating only the illusion of freedom of choice, when discussing the clients' right to discontinue treatment or life support. We support the emergence of an ethical debate which will properly engage the question of the extent to which such choices are constrained, if the resources necessary to sustain a high quality of independent life are not available.

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Debates Across Social Movements on Reproductive Technologies, Genetic Engineering, and Eugenics

by ***Theresia Degener****, LL.M., Frankfurt, Federal Republic of Germany*

An Example of the Coming Together of the Women's and Disability Movements in the Field of Reproductive Technologies, Genetic Engineering and Ethics

I have been asked to talk about what is going on in the West German disability movement and in the international network FINRRAGE with respect to the ethical issues of reproductive and genetic technologies.

When I speak about these movements, I speak as a member rather than a representative, simply because neither the West German "Forum of Cripple- and Disability Groups" nor FINRRAGE has elected representatives such as presidents or directors. These are more or less what in the United States might be called grass roots organizations.

1. FINNRAGE

Finrrage stands for Feminist International Network of Resistance Against Reproductive and Genetic Engineering and it is an international network of feminists who are critically concerned with the development of reproductive and genetic technologies and their effects on women. Finrrage emerged with the growing awareness that it is time to question the assumption that the new reproductive technologies (NRT) and genetic engineering (GE) are benign or neutral. Rather they have to be seen as (new) means of controlling population quality through controlling women's reproductive capacity.

Feminists in Finrrage are scientists, scholars, health politicians, lawyers, sociologists, biologists, etc., as well as "non-professionals". Some women work within their country's scientific community or hold positions in the health care systems; others have left those circles or positions as a result of their study.

Background

When the network was founded, which was at the second International Interdisciplinary Congress on Women in Groeningen, the Netherlands in April 1984, it was first called FINNRET (Feminist International Network on New Reproductive Technologies). The network took the initiative to monitor developments in reproductive and genetic engineering and their effects on women worldwide. It soon became clear, however, that the interrelationship between reproductive technologies and genetic engineering have to be more emphasized in order to analyze the political impact of these technologies and the harm they do to women.

At the network's first international conference in 1985—called the Women's Emergency Conference on the New Reproductive Technologies—74 women from 20 countries met in Vållinge, Sweden to discuss the links between Genetic Engineering and Reproductive Technologies.

Finrrage is an international network of feminists who are critically concerned with the development of reproductive and genetic technologies and their effects on women.

These two areas of science which may have seemed to be unrelated in the beginnings have soon converged and depend on each other. The NRT such as IVF (in vitro fertilization) provide the raw materials (eggs and embryos) for genetic research and experimentation on embryos and human beings. And vice versa, the experimentation with the NRT depend on

Women to whom these technologies are applied find themselves reduced to egg donors, (surrogate) wombs, fetal environments, reduced to interchangeable raw materials in the process of human reproduction. Women regain the status of a person only when it comes to the point of making selective (and mostly eugenic) choices, such as selective abortion.

the results of these genetic researches. The best example for this is the development of what is called preimplementation diagnosis. This form of prenatal diagnosis implies that IVF embryos are genetically screened before they are reimplanted. Thus the "fittest" embryos can be chosen within the IVF procedure in order to improve the present low success rate of IVF.

The clarification of this interrelationship led to a change of the network's name to Finrrage.

Current Activities

National contacts were chosen for 20 countries who started to send to the international coordinator information from their media, medical and scientific sources, and news on feminist actions. The international coordination group which until recently has been in England (Birmingham/London) has been assembling these and distributing information packets to the national contacts. The national contacts in turn have been distributing and publicizing this information in their own countries. Finrrage members also published books, articles and started the new journal: *Reproductive and Genetic Engineering: Journal of International Feminist Analysis.*

Meanwhile there are national contacts in about 30 different countries. The international coordination now resides in Frankfurt, West Germany.

Disability Link

Since the Emergency Conference there have been many other important meetings and conferences Finrrage has been involved in where we shared our experiences with respect to these technologies in our countries. And what we came to see is that NRT and GE especially affect the social status of two population groups all over the world: women and disabled people (which of course are not distinct separate groups).

They affect women in terms of control over their reproductive behavior and they affect disabled people (as well as women in countries like India, where femicide is being promoted through the use of pre-selection and sex determination) in terms of eugenic population policy.

This analysis is a result of a certain feminist approach to the reproductive ethics. This approach analyzes the interrelationship between NRT and GR, the historical background of these technologies and the social, economical and ecological context in which they are developed and applied. Because of this comprehensive feminist approach, women of Finrrage realized that what is promised by those who support these technologies, i.e., that these new technologies enable women to exercise greater control over their reproduction and thus give them greater liberty—is false. As Gena Corea, one of the founders of Finrrage said at the West German conference last October: ". . .all that women gain with these technologies is 'junk liberty'".

These technologies deprive women of what has been once their domain: childbearing and motherhood. Women to whom these technologies are applied find themselves reduced to egg donors, (surrogate) wombs, fetal environments, reduced to interchangeable raw materials in the process of human reproduction. Women regain the status of a person only when it comes to the point of making selective (and mostly eugenic) choices, such as selective abortion.

When fetal defects have been prenatally detected, women are charged with the responsibility to decide whether or not to carry the pregnancy to term. But again, women are not

. . .these technologies force us to view disability as a biological risk, as a danger of nature which has to be overcome by eliminating the carriers of these human traits. Thus the development and application of these technologies contribute to the decreasing social acceptance of disabled people.

given greater choice or liberty. What is given to women by these technologists is more "scientific" information on possible disorders or disabilities of their potential child. And all women are left with is being in charge of quality control over their offspring, because having a disabled child is not a true option to them.

Every woman knows what the social status of disabled people and their families is all over the world: it is determined by discrimination, being foreclosed from the mainstream of society and being denied basic rights.

These social conditions have not been created through the introduction of the NRT and GE. As we have heard at this conference, these social circumstances characterize the history of disability in human society.

Biological or Social Issue?

But what has been introduced or better reinforced by the introduction of these new technologies is to see disability from the perspective of biological determinism thus reducing the complex issue of disability. Disability is seen as an entirely biological issue (genetic or nongenetic). Totally ignored are those social circumstances that make disabled people suffer, such as institutionalization, environmental barriers, etc.

Because the NRT and GE are designed to overcome nature—in an exploitive patriarchal sense—these technologies force us to view disability as a biological risk, as a danger of nature which has to be overcome by eliminating the carriers of these human traits. Thus the development and application of these technologies contribute to the decreasing social acceptance of disabled people.

The underlying values are those of eugenics, a theory that has been used to justify physical and social oppression of minorities and women for more than a hundred years and which was most brutally realized within Nazi Germany's racial hygienic policies.

Women in Finrrage have realized that the NRT and GE by no means give greater choices to women in terms of avoiding having a disabled child. As a result of intense debates between disabled and nondisabled women within Finrrage, feminists in some countries started to think over the concepts of reproductive control and free choice. We have realized that these concepts, as they are applied especially by supporters of these technologies, relate to very narrow visions of what kind of family is "normal", what kind of children are "valuable" enough to be born, and what sort of responsibilities and roles women should have.

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Valuing Diversity

In response to eugenic and patriarchal ethics of the NRT and GE, women in Finrrage promote a feminist ethic which values diversity and takes a more comprehensive look at the world.

The resolution which was passed in Comilla, Bangladesh this March incorporates the concept of such a feminist ethical view, i.e., with respect to disability. Relevant sections are:

"3. *Genetic and reproductive engineering are part of an ideology of eugenics which we* *oppose. In this ideology human beings are viewed as inherently inferior or superior. This leads to degradation, discrimination and elimination of oppressed groups; be they women, disabled, people of certain colors, races, religions, class, or caste. . . .*

8. . . . . Our present finite world of resources offers a richer diversity than that promised by genetic engineering with its selective, and patriarchal philosophy.

9. Genetic and reproductive engineering are a product of the development of science which started off by viewing the whole world as a machine. Just as a machine can be broken down into its components, analyzed and put back, living beings are seen as consisting of components which can be viewed in isolation.

. . .

26. We are against any kind of bias and discrimination against disabled people including that of genetic screening and counselling. We particularly oppose the human genome project within this context. Prenatal diagnosis, genetic screening and genetic counselling do not offer the solution for disability. Instead we demand the elimination of hazardous drugs, radiation, hazardous chemicals at the workplace and in the environment and a solution to the problems of malnutrition and preventable infectious diseases.

27. Disabled people must be integrated into society and accorded full respect as human beings. The responsibility for caring for the disabled must be of social rather than of individual concern ."

2. The Activities of the "Forum of Disability Groups" with Respect to Eugenics and Euthanasia

The "Forum of Disability Groups" represents the more militant part of the West Germany disability movement. The organization has its roots in activities which were undertaken in 1981, the International Year on Disability. We found that the celebrations and shows which were organized by the government and traditional disability organizations did not help to improve the situation of disabled people in West Germany. We found, that instead of raising an awareness of disability-based discrimination among the general public, these celebrations and shows disguised the real shortcomings of West German disability policy, e.g., institutionalization, separation with respect to education and other forms of discrimination. We expressed our view by disrupting the national opening celebration in the beginning of the year and organizing a "cripples' tribunal against human rights violations with respect to disabled people" in December of 1981.

Since then the forum has undertaken many activities. Working closely together with the Greens has given us a louder voice. Presently local disability groups in approximately 20 towns are involved within the forum.

a. Debates Across Movements

The issues of eugenics and euthanasia have been raised within the context of two debates in West Germany.

In the beginning of the 80's fascism under Nazi Germany became the topic of public debate to an extent that had never been reached before. This was the second wave of anti-fascist debate and publications about Nazi Germany. The first took place in the 60's and was one of the topics of the students' movement. That debate, however, was confined to the Holocaust against the Jews and the SS State. During the last years, many historical studies on racial hygiene, euthanasia and forced sterilization were undertaken and there was a boom of publications concerning this issue on the market. A number of authors studied the elimination of disabled people through the Nazis' "euthanasia" programs, e.g. the ideological background, the structure of enforcement, the effects on society's view on disability, etc. Thus, for the first time, the situation of disabled people under Nazi Germany and especially the topics of "euthanasia", forced sterilization and the ideology of racial hygiene were discussed.

. . .more and more feminists became convinced that selective abortion based on disability screening discriminates against disabled people and is closely connected with the ideology of eugenics, which was the ground on which racial hygiene grew.

The second debate which also started in the early 80's relates to the NRT and GE. This debate has especially taken place within the women's movement but also reached groups beyond. At several conferences and meetings the effects of these new technologies especially with respect to women and disabled people were discussed. A major topic has been the use of amniocentesis and similar prenatal diagnosis methods for the purpose of screening of disabilities. The women's movement—and especially those groups involved with Finrrage—developed a very critical attitude towards these technologies. Starting from the rejection of pre-sex-selection and sex-determination, more and more feminists became convinced that selective abortion based on disability screening discriminates against disabled people and is closely connected with the ideology of eugenics, which was the ground on which racial hygiene grew.

The disability movement has been involved in both debates from the beginning. Thus, during recent years, different social movements, e.g. anti-fascist groups, women's groups and disability groups have been coming together in West Germany. In sharing our views on these topics we were of course not always of the same opinion and the debate is still continuing. But what became clear is that the issues of eugenics and euthanasia as well as the question of reproductive freedom and selective abortion have to be viewed and analyzed from a historical political perspective.

b. Development of Human Genetical Science and Policy in West Germany

It was only in 1972 that the first genetic counselling office was opened to the general public in West Germany. The predecessors—the racial hygiene offices of the Nazis—were closed in 1945. They had been involved in the Nazis' programs on forced sterilization and "euthanasia" which ended in the sterilization and killing of hundreds of thousands of disabled people (or people who were called socially disabled). While science on human genetics soon regained respect and recognition within the scientific community, it took some more time until their counselling offices could be opened to the public in West Germany.

By the time activists of the disability and anti-fascist movement started to study and publish on race hygiene and euthanasia in the early 80's there were about 40 genetic counselling offices all over West Germany.

Those who took a close look at the publications of genetic counselors as well as to their records found that there was little difference between the racial hygiene institutes and modern genetic counselling offices, neither with respect to ideology nor with respect to personnel.

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(1) From Racial Hygienicists to Human Geneticists

The most famous example of personal continuity is the career of Ottmar Von Verschuer.

In 1942 he became director of the Kaiser-Wilhelm-Institut in Berlin which was one of the central research institutes of anthropology. Before that time he was the head of the racial hygiene institute in Frankfurt where he worked closely together with Josef Mengele who later became "famous" for his experiments with *human beings in Auschwitz.* From Auschwitz Mengele provided Von Verschuer with "research material" such as the eyes of gypsies who had been murdered in Auschwitz.

Unlike Mengele, Von Verschuer did not have to hide in order to escape prosecution after Germany had been freed. In 1951 he became the director of the institute of human genetic science in Münster. In 1958 this institute published a study on the benefits of infanticide. The study gave an estimate of 16,000 (disabled) children who could be "beneficiaries" of such a program.

Another example is the biography of Fritz Lenz. He was the co-author of books on human genetics that later became a standard reference of the Nazis. In 1937 he was involved in the program on forced sterilization of colored children and he was also engaged in the group who drafted a law on "euthanasia", which however never came into effect. Already in 1946 Lenz became a professor on human genetics in Göttingen.

Heinrich Schade, who was assistant to Von Verschuer in 1936 at the university of Münster and in 1942 followed him to the Kaiser-Wilhelm-Institut in Berlin followed the same career as Lenz and Von Verschuer. Despite his activities in the Nazi's program on forced sterilization and other race hygiene programs he became professor of human genetics at Göttingen University in 1966.

These are only a few examples of those who had served the Nazis and without a break could continue their career in post-Nazi Germany.

To discuss in detail the impact of these people's work on Nazi politics would exceed the subject of this paper. Nevertheless, it should be kept in mind that there was a close link between the eugenic programs of the Nazis, e.g. forced sterilization and "T-4 program" (euthanasia) and the Holocaust. A link with respect to conceptional preparation, as well as institutional and technological preparatory work.

(2.) Ideological Continuity and Development of Neo-Eugenics

The ideology of these "scientists" did not change either. What had been called racial hygiene under Nazi Germany (and earlier) was now called human genetics but the publications in this field still focused on the "burden" disabled people, antisocial poor people and foreign people place on society. Openly, human geneticists discuss how to get rid of these problems: the dominant means being sterilization and genetic counselling.

Genetic counselling offices were charged with genetic counselling (and registration of people with hereditary disabilities) as well as sterilization recommendations. In order to distinguish their work from their predecessors, it was claimed that genetic counselling, prenatal screening, and sterilization of disabled persons, as performed by these offices (and connected clinics) were only for the good of the individual and his/her family. Not to improve the genetic pool of the Germans, but rather to increase the individual's happiness was the said purpose. That their work had nothing to do with what the Nazis did could be seen from the fact that their scientific bases were totally different from racial hygiene.

However, the public was confronted with the opposite, when in 1984 the work of one office in Hamburg-Barmbeck gave rise to a scandal. The head of the office (Stockenius) had published a book on "Debility of Unclear Genesis" which was criticized by disability activists because of its eugenic contents.

The documents, published in newspapers and other publications, revealed that the counselling criteria of Stockenius and her staff were the same as the Nazis had used for decisions on forced sterilization and euthanasia. Stockenius recommended the sterilization of people with 'conspicuous' family histories, such as: "parents very simple", "cousin a permanent student", "older brother nervous", "grandfather and his brother alcoholics", "uncle suicidal", etc.

This approach to disability is biological/genetic instead of viewing disability from a social perspective. Societal discrimination against disabled people thus can be justified by biological cause and abolished by eliminating the carriers of disability.

During the Stockenius scandal more publications by human genetic counselors became the targets of criticism, showing that Stockenius' ideas represented only the tip of the iceberg–an iceberg that also covers the development of what has been called the neo-eugenics movement.

Advocates of neo-eugenics are gene technologists, social biologists, economists, or professionals in the field of reproductive health and ethics. The ideology of neo-eugenics unites modern and classic arguments and goals and can be summarized in the following aspects:

- The paradigm of genetics has shifted. Control over reproductive behavior is no longer sought by means of invasive state programs but by the establishment of individual self control.
- The improvement of German race or what was called "Volk" is no longer the focus of population policy. The target is now the individual and his/her economic interest (not to have a disabled child).
- The new/classic goal is the centralized registration of all people with "genetic disorders" in order to improve scientific knowledge and at the same time "advise" people with respect to their responsibility of their personal life style.
- Two classic arguments of eugenics are stressed:

The first argument relates to advancements in medical technologies. It is said, that because of these technological developments more disabled people survive today, who in former times would have died because of "natural selection". With the improvements in medical technologies these disabled people now reach reproductive age and are able to procreate, the supposed result being the birth of even more disabled individuals. Such a development is said to be against the interests of society as well as against the interest of the individual being born disabled.

The underlying assumptions are claimed to be as simple as "rational": (a) An increasing disabled population group is a burden to society and thus is detrimental to the happiness of all; and (b) disability itself is always a tragedy for a human being and thus is detrimental to the happiness of the individual.

While those assumptions might be shared by many nondisabled people, they nevertheless are based on eugenic ideas. This approach to disability is biological/genetic instead of viewing disability from a social perspective. Societal discrimination against disabled people thus can be justified by biological cause and abolished by eliminating the carriers of disability.

Such a perspective is far from accepting disability as just another state of being, similar to race or gender. To compare disability with race or gender may be especially important within this context. It is not by accident that racism and sexism have their roots in eugenic argumentation as well.

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The second argument is as old as the first and both are commonly used together. It is the argument of the limited resources a society can spend on the general welfare relating to the fact that advancements in medical technology and other fields have increased the costs of medical and social care. Because of this development—which in West Germany is called "cost explosion in the field of medical care"—a new reflection on how resources are spent is being demanded.

These "new" reflections often result in publications like those of Von Stackelberg's. He computed the exact financial burden a disabled person places on society during his/her entire life. In 1980 he won a prize for his dissertation on cost-benefit analysis of genetic counselling.

c. Debates and Activities Across Movements

As a result of this analysis, e.g. that there was no real break between racial hygiene and human genetic science in West Germany, many meetings and conferences were held in which different groups and movements participated. While the most intense debate took place at the two national women's conferences against GE and NRT,(supra) between disabled and nondisabled feminists, other groups—church groups, unions, special education departments, and many student groups and especially the Greens!—also have been involved in the debate.

This discussion has been going on for several years now. Since 1984/5 at least once a week a meeting or panel discussion on these issues have been taking place somewhere in West Germany. Now there are several groups in West Germany who are concerned and aware of the developments with respect to euthanasia and eugenics. They represent an important addition to some other developments in West Germany.

Certain groups for almost a decade now have spoken out in favor of euthanasia and forced sterilization of mentally disabled people. In fact in 1982 and 1984 newspapers and TV frequently reported about cases of (illegal) infanticide—e.g., the killing of disabled newborns in hospitals—and (illegal) forced sterilization. One TV show, for example, reported that in the town of Hamburg about 50% of all disabled female minors in special schools were sterilized. And an estimate was given that approximately 1000 disabled persons per year are sterilized; often without informed consent.

In order to legitimize this illegal practice, a law on forced sterilization of mentally disabled individuals has been drafted and is now on the floor of the Federal Parliament. Unfortunately, it looks like it will soon be passed. It goes without saying that these developments go hand in hand with social cutbacks.

However, those critical groups mentioned earlier seem to be gaining influence as the debate goes on. A few weeks ago these groups formed a coalition in order to prevent an international symposium on biotechnology and mental disability that was supposed to take place in Marburg, a small town in Hessen near Frankfurt. As guests of the Dutch Bishop-Bekkers Institute and the German Lebenshilfe—the largest organization of parents of mentally disabled in West Germany—experts in bioethics and medicine were to talk about whether or not newborn disabled have a right to live.

Among the invited experts was Peter Singer, Professor of Philosophy and Director of the Center for Human Bioethics at Monash University, Australia. He has published several books in which he proposes the killing of some disabled infants.

In *Should the Baby Live?* Singer tries to redefine what constitutes a person. Demanding the diminuition of the principle of sanctity of life, he rejects the assumption that a human being has a right to live merely because of his/her membership to the species of homo sapiens. Only a person would have a right to live and what makes a person, according to Singer, is the ability to develop "self-awareness, self-control, a sense of the future, a sense of the past, the capacity to relate to others. . .", etc. Consequently, according to Singer, it is no crime or wrong to kill a disabled infant that does not fulfill Singer's criteria for personhood. Singer thinks that some disabilities do not allow one to lead a "worthwhile, happy" life, among

The neo-eugenic ideology is based on the assumption that there are some disabled people who merely, because of their disability, don't have equal rights. Such a position should be called what it is: invidious discrimination against disabled people.

them severe cases of Down Syndrome and spina bifida.

But even if a disabled infant fulfills the criteria of a person, Singer finds other reasons to kill it. The interests of the parents, the value of the life of the 'next (nondisabled) child', and the interest of society, he says, may outweigh the disabled infant's right to live. As an additional justification he also uses classic cost-benefit arguments.

Our coalition in West Germany decided that we were not willing to give room to such a "debate among experts" and decided to prevent the symposium from happening. The coalition encompassing the disability and women's movement, the Greens, unions, anti-fascist groups and special education teachers, received a great amount of media attention. Because our protest grew from day to day, the symposium finally had to be cancelled.

The day the symposium was supposed to be opened in Marburg, we organized an anti-symposium at which we explained our attitude, e.g. that the right to equality and life of disabled people is more important to us than the right to free speech of 'experts' like Singer. This meeting was very successful, with more than 300 people from different groups participating.

Since then, the subject has been in the media in West Germany. The reports are not always in favor of our protest. Singer has many advocates in West Germany, but our protest has been recognized and wherever there is a report, meeting or TV show at least one member of the disability movement is being heard.

People who disagree with our disruptive protest argue that it is only in Germany that this topic cannot be debated. In other countries, like the United States, the Netherlands or Great Britain, they say, the debate has already reached a very sophisticated level. In saying this, they argue that the modern debate on euthanasia has nothing to do with what happened in Nazi Germany.

I agree that Singer, who claims to be anti-racist and anti-sexist, should not be called a fascist. In his book *Should the Baby Live?* he talks about Nazi Germany, racism and sexism and takes a different stand with respect to these ideologies.

It would take another paper to go into details with respect to Singer's ethics. But what we can already see from those quotations I have cited earlier is that Singer in his argumentation comes close to what I have called the neo-eugenic ideology. This ideology is based on the assumption that there are some disabled people who merely, because of their disability, don't have equal rights. Such a position should be called what it is: invidious discrimination against disabled people.

German history and the study of Nazi Germany, I think, is the reason why the disability movement and other critical groups in West Germany have developed a high level of sensibility and awareness with respect to this topic. However, it would be wrong to think that because of this history, it is only in Germany that those positions on eugenics and euthanasia are dangerous.

Many other countries have had eugenic movements in the past—in Europe as well as in the United States. Unique about German history is that those ideas have been realized. But apart from history, I think that ideas like those proposed by Singer are not less dangerous or more easily disputable in any other country.

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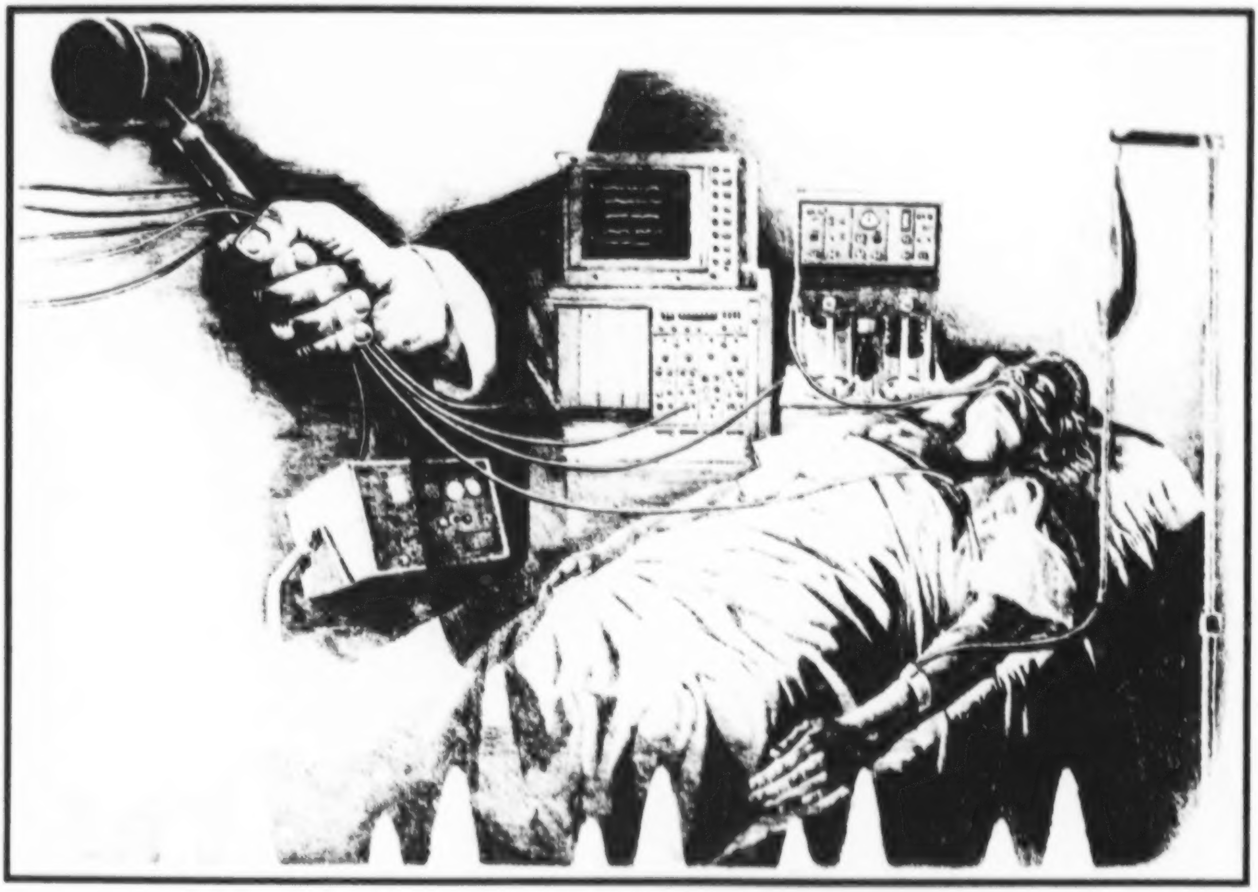
Section 3
Conference Commentaries



Drawing by Tim McWilliams, *American Medical News*, January 3, 1986

The Meeting of Disability and Bioethics: A Beginning Rapprochement

*by **Adrienne Asch**, New Jersey Bioethics Commission**

The Intellectual Context

When I first began teaching a course on The Disabled Person in American Society in 1982, I looked for philosophical material that would illuminate what I believed to be central questions of the disability experience and of social policy. What *was* health?; when was a human variation a "disease" or a "disability"?; what were the obligations of doctors and rehabilitation professionals toward the disabled people they sought to help?; how much of a nation's resources should be committed to creating a truly accessible society?; if there were not enough rehabilitation services for all who could use them, who among the potential beneficiaries should receive them?; should an intellectually alert but physically disabled person be allowed or assisted to end life?; should newborns with life-threatening condition receive medical treatment despite their parents' objections?; should relatives or legal guardians be able to forego treatment for a man with Down syndrome who developed cancer?

The field of bioethics contained writings by thoughtful scholars that bore directly on these matters, and I incorporated several sections out of a standard anthology in bioethics into my required reading. I quickly realized that although bioethicists were the people who were discussing these questions, they were not always doing so in ways I found satisfactory. It seemed to me that many scholars were tackling fundamental questions about disability but omitting from their analyses the social, as opposed to narrowly medical, aspects of life with disability. Many also seemed unacquainted with how people with various disabilities felt about their lives or why they felt what they did; and there was nothing in bioethical discussion suggesting familiarity with the movement for independent living and disability rights.

In 1982 disability activists were fighting to retain hardwon legal rights and social services in the wake of Reaganomics, and researchers were studying how the new laws were affecting disabled people and the society into which they were finally gaining some access. Disability rights and bioethics had not, so far as I could tell at that time, discovered one another and recognized how inextricably intertwined was philosophical discussion with political struggle. But when the media dramatized the cases of Baby Doe, Baby Jane, and Elizabeth Bouvia, both bioethicists and disability rights activists reacted strongly, and not always in harmony. At the same time people who believed both in women's rights to choose abortion and in disabled people's rights of life discovered a tension in much pro-choice rhetoric hailing abortion to avoid "the tragedy of a woman's bearing a 'defective' child." Suddenly disability rights activists were at odds with feminist allies and also with a medical profession that believed in abortion as a legitimate method of preventing disability.

> *When the media dramatized the cases of Baby Doe, Baby Jane, and Elizabeth Bouvia, both bioethicists and disability rights activists reacted strongly, and not always in harmony.*

Conference Overview

The conference sponsored by Rehabilitation International, the World Institute on Disability,

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Institution is for identification purposes only; opinions are those of the author.

Personal decisionmaking, whether about treatment for newborns, the morality of prenatal testing and selective abortion, or about aiding people with disabilities to end their lives provoked the liveliest discussion.

and the World Rehabilitation Fund in conjunction with the Second Annual Meeting of the Society for Disability Studies attests to these significant intellectual and political developments. Its sponsors represent major centers of activism and scholarship in all aspects of disability nationally and internationally, and they ensured participation of researchers, service providers, and consumers from the United States and much of the developed world at this forum on ethical issues in disability and rehabilitation. The emotion sparked by the controversial cases of Baby Doe and Elizabeth Bouvia erupted at this 1989 meeting, demonstrating how central are these life-and-death issues and how divergent can be the frameworks from which disabled people and doctors sometimes perceive them. And less sexy but at least as critical, dilemmas of resource allocation and justice in access to technology and services began to get the airing that will assure increased work in these areas by those committed to improving life for people with disabilities.

Personal decisionmaking, whether about treatment for newborns, the morality of prenatal testing and selective abortion, or about aiding people with disabilities to end their lives provoked the liveliest discussion. Presentations of these topics did not always reflect the range and diversity of views among those who have worked on the issues.

Opening Session

The opening session highlighting treatment decisions about disabled newborns offered the best balance between U.S. and Europe, the past and the present, research, policy, and politics. Hugh Gallagher opened by reviewing his important research on how political philosophy affected medical practice in Nazi Germany. His work is a valuable addition to the scholarship of perhaps better-known researchers Lifton and Proctor, whose recent books document the horrific uses to which medical science may be put and warn us of the dire consequences of a past slide down a slippery slope. Researchers Ernlé Young and Daryl Evans presented their findings about decisionmaking for newborns with disabilities in Great Britain and Sweden (Young) and in the U.S. (Evans) in the 1980s. Each had some apprehension about whether laws such as the Child Abuse Amendments of 1984 could effectively guide parents and professionals in deciding about medical care in these situations, but other panelists and audience members responded with more favorable interpretations of the law as protecting the interests of these infants in an opportunity to medical care that would aid them to a chance at life.

Open Forum

Prenatal diagnosis and selective abortion occupied much of the open discussion, but unfortunately, even for this skeptic, that discussion was a bit polemical. Although many professionals among panelists and attendees needed to hear people with disabilities say clearly that they saw nothing tragic or immoral about bearing children who would also be disabled, the supporters of screening and selective abortion were either absent or silenced. These techniques would not have been developed had medical science not believed that they could reduce the totality of the world's physical pain, psychological anguish, and social and economic expenditures. Given the emotion generated by such a topic among people with disabilities who understandably may feel targeted by these procedures, it might have been worthwhile to build in a thoughtful analysis of the potential benefits to the individual and the society of such procedures before the opposition was unleashed. Technology, not its uses or unthinking misuses, became the object of hostility.

Closing Session

Most dramatic and problematic of the five sessions was the conference finale, a presentation of medical ethics in a rehabilitation setting. Those of us who hoped that *Whose Life Is It Anyway?* was a one-time work of theater and that Elizabeth Bouvia was a one-time real-life case learned otherwise. We also learned that the efforts made to alter the discussion of her circumstances in the media and in the fields of medicine and bioethics have not been entirely successful.

Physicians from the Craig Rehabilitation Hospital presented a specially-made video tape of a conversation recounting the hospital's work in 1988 with a man who became quadriplegic in an accident in which his wife also died. Through the videotaped conversation between two members of the Craig Hospital staff, we learned of the months of work with the patient who sought the hospital's cooperation in removing the respirator that assisted him to breathe. Hospital staff were clearly disturbed at such a request and spent many months with the patient before agreeing to honor it. Yet, as portrayed in the videotape, those months did not include reports of contact between the newly-disabled man and other spinal-cord injured adults who live outside of hospitals, maintain jobs, and care for their children. Although psychiatric consultation assured the patient's "competence" to make such a decision, that consultation did not include any assessment of what the patient knew of the problems and prospects of life with a disability. Nor did the hospital's ethics committee, as described in the videotape, insist that making a truly informed decision included assuring that the patient had been exposed to people who had lived for some years with quadriplegia or to knowledge about laws or services that might make possible reintegration into community life. Most poignant to this observer was that the patient, whose two children had just endured their mother's death, was never given any reason to believe that he, although disabled, might still offer love and support to his children and make a contribution to his family as well as to society.

> *What information constitutes that necessary for a truly informed decision? How should decisionmaking capacity be assessed in the wake of such major traumas as the death of a spouse and the acquiring of a severe disability?*

I suspect that neither the presenters not the conference planners were prepared for the response. Disturbing questions and harsh criticism turned to outrage from an audience that felt the professionals in a rehabilitation hospital were demonstrating that they, too, believed at bottom that life with disability might not be worth living and that it might be moral to lend their institutional support to someone who wanted not rehabilitation but death.

Bitterly attacked, the Craig presenters became understandably defensive and unfortunately reluctant to respond. To be sure, they probably did not know what had hit them, since they had come with a second case illustration that never got discussed. But if the discussion of Elizabeth Bouvia's circumstances had sufficiently penetrated the medical or rehabilitation communities, these long-time practitioners should have expected the questions and the attack and should have had explanations. Perhaps if the doctors had had the opportunity to hear the papers presented by Yolan Koster-Dreese, Peter Gow and Joseph Kaufert, they would have been better prepared for the reaction to their presentation. Perhaps the videotape, a conversation between two professionals well after the patient's death, did not report all the exploration between staff and patient and all the information conveyed. To be sure, a competent adult does have the right to refuse medical treatment.

Broadening Perspectives

Yet the Craig staff seemed not to understand the many concerns such a case engenders: What information constitutes that necessary for a truly informed decision? How should decision-

The energy, emotion, and controversy of the sessions on prenatal diagnosis, treatment for newborns, and life-and-death decisions by adults with disabilities testify to the urgency of continued dialogue on these matters.

making capacity be assessed in the wake of such major traumas as the death of a spouse and the acquiring of a severe disability? Was depression treated? Were stereotypes of disability challenged? In such a case as this, what is the proper balance of patient autonomy, professional responsibility, and state interest in protecting the integrity of the medical profession, the welfare of such innocent third parties as the man's children, or in preserving human life and opposing suicide?

In the few months since the conference, real-life cases and technological developments reveal the gravity and pervasiveness of the issues it raised. David Rivlin, a quadriplegic man in Michigan, succeeded in ending his life saying that life was not worth living. Larry James Macafee, residing in an Alabama nursing home, in September obtained a court order affirming his right to end his life as a quadriplegic, and that lower court order has been upheld by Georgia's highest court. Most bioethicists still talk about "the autonomy of the competent patient"; but some have joined with members of the disability rights community to ask about the quality of the service and information that precedes these life-ending decisions and to ask whether social circumstances that might be changed, rather than medical conditions that cannot, are responsible for decisions to die. These faint voices need to be louder, but they affirm that the field of bioethics can broaden its perspective.

The next conference needs to give more time to the access and allocation questions that face all the nations of the developed and developing world: How should finite resources be expended among all the types of health care, rehabilitation services, family support, and access needs that

Urgency of Continued Dialogue

The energy, emotion, and controversy of the sessions on prenatal diagnosis, treatment for newborns, and life-and-death decisions by adults with disabilities testify to the urgency of continued dialogue on these matters. The next conference needs more time for professionals to respond to the concerns of people with disabilities, and it needs more presenters trained in bioethics to give the particular issues their proper context. The next conference needs to give more time to the access and allocation questions that face all the nations of the developed and developing world: How should finite resources be expended among all the types of health care, rehabilitation services, family support, and access needs that compete for them? Where do these needs fit into societies fighting illiteracy, poverty, unemployment, and crime? Can we prevent competition for resources between one child needing a liver transplant and hundreds of women needing prenatal care to prevent illness in their children?

Future Agenda

The next conference also must give attention to the multitude of issues surrounding treatment decisionmaking for those who are not capable of making treatment decisions for themselves. These dilemmas arise not just for parents about their children but for anyone with a loved one whose Alzheimer's Disease has rendered him or her incapable of understanding the ramifications of complicated decisions or for anyone whose institutionalized mentally ill or mentally retarded relative develops a life-threatening medical condition. What should be the respective roles of family, of institutional staff, and of the state in promoting the welfare of someone without capacity? What should be a proper balance of respect for

These dilemmas arise not just for parents about their children but for anyone with a loved one whose Alzheimer's Disease has rendered him or her incapable of understanding the ramifications of complicated decisions or for anyone whose institutionalized mentally ill or mentally retarded relative develops a life-threatening medical condition.

the interests of an incompetent person, a family, and the society?

Representatives of governmental and private citizen groups involved in deliberating about these and other bioethics topics were at the conference, but a crowded agenda and vocal audience precluded them from saying all that they might have about their work or about how people with disabilities and rehabilitation professionals might increase their participation in such deliberations. These topics, too, deserve increased attention. If hospital ethics committees might make more careful and sensitive decisions in life-and-death situations if they knew more about the lives of people with disabilities, how should they get such information? What is the proper role of people with disabilities in ethics committees or in working with genetic counselors or parents of disabled newborns? And if there is a role for information about the lives of disabled people, what information? Who should provide it? How can it be assured that neither gloom and doom nor persistence-conquers-all will dominate the information presented?

These topics illustrate only some of the questions that arise and will profit from interchange between the rehabilitation professionals, bioethicists, people with disabilities, and families. Experiences of the developing world and of Asia, Africa, and Latin America need to be shared as well.

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Clearly this first conference deeply stirred those who attended it and raised some of the most important bioethics questions of the age. It is obvious that these questions need much more discussion and that many more remain to be addressed. It is to be hoped that future research and future conferences will further what was begun here.

A Plea for More Dialogue: Commentary on Ethics Conference

*by **Robert J. Slater**, M.D., Health Decisions USA, National Health Council*

This meeting was organized to provide an overview of historical and current trends and issues of the main factors influencing daily living with handicap. In attempting to reflect the outcomes and implications of this meeting, my principal concern is not to focus on the content and quality of the presentations. As reflected here by Martha Walker, the expectations of the planning committee's agenda were clearly fulfilled by the invitational presentations which were excellently developed to set the stage for discussions.

> *What seemed to be at stake were the very personal beliefs of numerous, articulate participants reflecting their criticism of social history and emerging current governmental policies. . .*

Rather, my main concern arose from the highly charged, frequently tendentious reactions from what appeared to be conflicting factions among the participants, all of whom represented the interests of people with disabilities. These reactions are reported eloquently in Martha Walker's Commentary and her emotional responses are shared by many. However, given the benefit of hindsight, I sense this discordance can be harnessed into constructive uses and could result in a fortunate, albeit fortuitous, opportunity for an extended, influential and catalytic role for the Society for Disability Studies (SDS) which was the venue of this meeting.

Clearly SDS has been organized to fill a void in the social dynamics of public and private programming in the United States for those with disabilities and all participants had a significant record of concern and involvement with these issues in past years. What seemed to be at stake were the very personal beliefs of numerous, articulate participants reflecting their criticism of social history and emerging current governmental policies involving ethical principles of autonomy, beneficence, personal fairness and distributive justice as these implicated costs and reimbursements, resource allocation, rationing and public attitudes.

On a number of occasions, efforts at dispassionate and objective analysis of ethical and practical issues was interrupted by subjective, frequently passionate interpretations so that achieving the larger objective of identifying policy potentials seemed to me to be endangered.

Edward Berkowitz(1) dealt with this phenomenon in a 1984 study which defined the contradictory views held by vocational rehabilitation bureaucrats who, in working with a medical model of the requirement of appropriate provider/client interaction, are frequently at odds with their beneficiaries who, in turn, are oriented to a civil rights ideology concerned principally with practical results of intervention. Berkowitz described how the objectives of the professional "dependency" programs, oriented primarily to psychological counselling for adaptation of the disabled to work, were at odds with the goals of the civil rights movement for financial independence. Thus Berkowitz interpreted the Vocational Rehabilitation Act of 1973 as productive of a program at war with itself. At this meeting some 16 years later, one had the odd feeling that "we have met the enemy and it is us."

An example of philosophical discord was reflected by the huge gap in belief, understanding and expectation of those who consider desirable the full scale treatment of imperilled newborns in our "Temples of Technology" as

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depicted by Daryl Evans in contrast to both professionals and "consumers" who would implement the Code Grey intervention out of a sense of beneficence to prevent unpredictably severe, life-long handicap. There is a sharp division between those who believe our resources (funding, personnel, equipment) should be rationed in favor of programs to prevent disease and disability versus interventions that increase the likelihood of major handicaps in young and old alike. Severe misunderstandings exist between the larger voting population which is searching for ways to enhance and pay for preventive and curative interventions to diminish disability versus some of those with handicap who believe their experiences have provided the opportunity to lead such a full life that given another chance they would opt to be disabled and even favor bearing handicapped children. Of course, differences of opinion on these matters exist among those who have disabilities.

The public question may well be raised about whether it is not one thing to have emerged from centuries of ostracization to major advances in social emancipation during the past 50 years and quite another thing early in this era of scientific advances and increasing cost/services constraints to have the public accept that handicap is a significantly desirable experience so therefore we should advocate more of it. As Irving Zola averred, "There are limitations to disability pride." I would query whether the depth and extent of such views could be reshaped and modified for practicality by means of extended dialogue among all of the players—providers and consumers.

How can we deal with these differences of belief beyond studying and quantifying them? What will be defined as a rational and ethical basis for maintaining or expanding and paying for programs of disability prevention, treatment and social support? How can the articulated concerns of the civil rightists be expressed in a manner most likely to achieve a favorable political response?

The identification of such questions as these and the means of resolving or at least coming to grips with them by generating civil and rational discourse about social alternatives and costs can surely be included as an objective of SDS within its context of study and enlightenment.

To achieve such an objective, SDS might best be cast in the role of special purpose catalyst in which critical questions are framed (not contested) and then taken out into the field for extended discussion among a collaborative consortium of agencies and forums already in existence. Thereafter the outcomes could receive final overview debate on an SDS agenda.

Inevitably our questions deal not only with acceptance of our wounds and pain (to paraphrase Martha Walker), a process more meaningfully accomplished by sharing experiences with comparable others. Our questions also deal with the ethical issues of what is right and fairest for all, even those yet unborn. Kenneth and Sara Vaux(2) have advocated that dealing with such complex ethical questions is most readily handled by examining the individual components involved in decision-making—the conceptual framework of:

- **instinctive:** one's instant gut reaction reflecting cultural and acquired beliefs;
- **professional:** the implications between and among involved professionals as well as the "doctor/patient" relationship;

By organizing extended discourse in a forum which permits deeply held beliefs and attitudes (instinctive, professional, political, transcendental) to be widely discussed, to share views with others in an atmosphere designed to enhance trust and understanding, "to walk a mile in the other's shoes", can one avoid the "numb criticism and fragile despair". . .

- **political:** institutional, agency and governmental ramifications, and
- **transcendental:** one's spiritual connectedness in frequently lonely or terminal decisions or experiences.

Such a system of classification greatly assists in clarifying what we are saying we believe. In contrast to the exactness of language and meaning in the biomedical sciences, the meanings and interpretations of descriptors in the psychosocial sciences involving ethical data and decisions very widely from person to person. Thus any dialogue on an issue that permits verbal and nonverbal interplay between involved professionals and consumers will increase trust and understanding.

The growing field of ethical decision-making has spawned ethics committees in hospitals, churches, law offices, business corporations and other special purpose environments such as the American Association of Retired Persons, the Veterans Administration and voluntary health agencies. Perhaps the most politically sensitive and representative arenas are the state-based bioethical commissions which bring together in community settings a wide range of professionals and consumers to debate specific issues such as limitation on use of Medicaid funds for transplantations recently brought to legislative response in Oregon. Such one-day sessions convened around the state lead to consensus building in a concluding "Parliament" with resultant outcomes from this wide base informing both the public and the legislature. The American Health Decisions consortium now includes some 14 states.

A more in-depth dialogue is achieved by the National Health Council format—Health Decisions USA—which is based on facilitated 20 person groups, half of each group being professionals (doctor, nurse, social worker, clergy, lawyer, health care administrator) and the other half patients, family, significant others. Using sharply focussed case studies and relevant background material in an Issues Book, these dialogues have been optimally scheduled for a two hour session per week for 6 successive weeks.

By organizing extended discourse in a forum which permits deeply held beliefs and attitudes (instinctive, professional, political, transcendental) to be widely discussed, to share views with others in an atmosphere designed to enhance trust and understanding, "to walk a mile in the other's shoes", can one avoid the "numb criticism and fragile despair" noted by Martha Walker as an outcome of brief encounters in a fast moving agenda. The Health Decisions, USA (HDUSA) model is widely adaptable to special purpose agenda of the voluntary health agencies, professional associations, religious and educational institutions.

If SDS (or another designated organization of persons with disabilities) were to consider such consortial activity as testing problems with state members of American Health Decisions as one of its operational modes, its annual meeting or other special forum could function like a Parliament and generate a sense of broad public thinking on specific concerns of the disabled perhaps using the HDUSA format.

There is an unusual opportunity for some organizations to be central to review and make recommendations on matters dealt with by the basic and applied sciences of disability. By maintaining a firm identification with the medical and social issues arising from congenital and acquired dysfunctions, as well as the social issues unique or common to these entities, the Society can move to a position of influence based on a reputation of rigorous examination and debate of major issues resultant to impairment of function.

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Healing Our Wounds

*by **Martha Lentz Walker,** Ed.D., C.R.C., Professor, Kent State University*

Background

As I prepared for participating in the Symposium, I had no inkling of how wounded I would feel upon my return. The impact of the Symposium was immediate and lasting. With this reaction, I hope to be part of my own healing and, perhaps, of others.

My expectations of the Symposium grew out of my role as a rehabilitation educator. For 20 years I have taught prospective rehabilitation counselors, believing ethics a subject difficult to teach and harder to model. I have used a videotape made at the University of Texas, Galveston, called *Please Let Me Die,* with beginning students in a course named Psycho-Social Impact of Disability. The film raises the conflicting moral principles of beneficience and autonomy through the experience of a person badly burned and disfigured, who asks that debridement be discontinued and that he be allowed to return home to die.

The film is deeply disturbing, confronting students with an ethical dilemma. Purtilo's (1983) monograph on humane health care values:justice, liberty, and compassion becomes quite real in the context of student discomfort. While the videotape dramatically raised ethical issues, I was bothered that few of our students would ever be involved in an intensive care situation, where the choices were so pressing. Rehabilitation counselors encounter lower profile ethical problems, more *how* a person will continue with life, not *whether* life will continue. As an educator, I hoped to find new and more work related examples for my students.

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> *We are entering an era of standardization and uniformity of medical procedures, predicting that patients will have less choice in a technologically oriented, computerized health care system.*

It seemed to me that the world was tilted toward Denver when I read the preliminary program. I had met Peter Gow in New Zealand and I knew him to be a physician of great conscience, practicing respect for others and providing communication opportunities for those with least voice in New Zealand: Maori and Pacific Islanders. I also had great respect for Adrienne Asch and Judy Heumann, as learned and articulate champions for person with disabilities. Irving Zola, Harlan Hahn, and Ernlé Young had taught me and my students through their writings, and from the titles of other contributors, I was certain this would be a bona fide world class symposium.

In addition to my search for instructional examples, I expected to learn more about macro issues, and followed Peter Gow's reading suggestions. On my flight to Denver, I began with Mooney and McGuire (1988). They warned that we are entering an era of standardization and uniformity of medical procedures, predicting that patients will have less choice in a technologically oriented, computerized health care system. My reading confronted me with the dilemma of harmonizing the individual good with the common good, in an era of shrinking resources.

As I read further, a related problem emerged. We have no social policy requiring an assess-

> *The best of technologies are still administered by human beings, professionals who struggle daily with the possibility that beneficence has been transformed to malfeasance, because treatment is continued.*

ment of technology before it is used (Mooney and McGuire, 1988). Vuori (1988) discussed technology assessment as well, as "policy oriented research which systematically asseses the societal consequences of the introduction and use of various technologies (p. 6)." My expectation was that the idea of harnessing technology through assessment of its effectiveness would be a dominant focus of the Symposium.

I read on, faster, as the airplane neared Denver. The writers presented strategies for clinical review in quality assurance (Shaw, 1986). They explained the categories for ethical decision making (Jonsen, et al, 1982) and the cost effectiveness of rehabilitation (Ostrow, et al, 1987). I arrived in Denver feeling somewhat confident that I had a rudimentary vocabulary and understanding, and I was impressed by the logic of the writers.

My equilibrium was soon to be rocked, however. While the titles of the sessions had a comforting, academic ring, the sessions later that day began a collection of "laser beams," searing questions and statements made during the Symposium.

First Session

In one of the opening sessions Daryl Evans discussed his research regarding "overtreatment of imperiled newborns" and the effects of Baby Doe legislation on health care personnel. "Temples of technology," Evans called the hospitals where infants born with spina bifida were treated. Nurses felt they were "medically torturing" children through overtreatment. The results: nurses who chain smoked, who had tremors, and high rates of absenteeism. And, even in the temple of technology, the human factor prevailed. Nurses were making the decisions by walking more slowly when an infant was obviously in respiratory distress. The "slow code" or "grey code" was the nurses' answer to an ethical dilemma. The best of technologies are still administered by human beings, professionals who struggle daily with the possibility that beneficence has been transformed to malfeasance, because treatment is continued.

During Dr. Evans' presentation, I sat next to a woman with spina bifida. How difficult to take a rational view of the nurses' decisions, sitting beside a person who probably does not know the decision path that made her presence possible. For me, the consequences of the slow code were personified by her presence. My discomfort was increasing. Dr. Evans' statement that "the effect on health personnel of federal surveillance regarding treatment was that you walk more slowly," controversial as it was, felt like a laser beam, in the presence of my neighbor.

Ernlé Young was next in presenting his research on the treatment and non-treatment decisions for low birth weight infants in three countries. The national differences seemed attributable to varying health care systems, the presence of pro life groups, and legal liability. Young's conclusions included the admonition that ours is an era of shrinking resources, that the threshold of eligibility for intensive care will be raised. He ended by stating that we must redefine the nature and significance of autonomy. Autonomy does not give a parent the right to practice medicine without a license. Young urged collaborative relationships, in which neither parent, patient, or health professional is subservient. "Unbounded autocracy" of parents or patients does not contribute to collaboration, Young said. Again, I was acutely aware of the listener to my right, wondering what she was thinking about the limits of freedom Young described. I felt a second laser beam.

Adrienne Asch had also been listening and responded, as I imagined the woman to my right would have: "with all the imperfections and bad handling of the Baby Doe decision, I think it is a good decision." For Asch, the law does not require overtreatment, and if the law is being misused "we need to infiltrate the bioethics profession," insuring that they do not equate life with a disability with torture or tragedy.

Second Session

We moved to another room, and to another level of the discussion, where Peter Gow and John Mather dealt with the allocation of resources. Peter Gow was saying that Americans were going to have to do without some of the "quality" they demanded in health care, and John Mather outlined the Federal policy calling for health care containment, despite 37 million Americans without health insurance. Mather talked of "bad manners at the health care trough," of the marketplace mentality which has determined the mix and availability of health services in America. "The United States is profilgate in its use of wealth," Mather said, and predicted that the notion of constrained resources will not be readily adopted. We need better socio-ethical theory, Mather said, in which fairness and equality prevail. Already, published procedures for cost effectiveness indicate that we will approach a socio-ethical theory through evaluating technology efficacy. No laser beams here, but a brighter operating room.

Robert Slater, as reactor to the presentations, called for "parliaments for rational discussion," a representative process through which confrontation could be reduced to debate. Dr. Slater was unaware of how relevant this statement would prove to be for the Symposium, as he offered a model for using the democratic process to reach social consensus on priorities for health care (Criggar and O'Malley, 1988).

Adrienne Asch, impatient with this macro analysis, reintroduced the laser and challenged the group with a series of questions. "Why think about health policy? Health decisions are personal and political. What are decisions going to mean to individual families?"

> *Yolan Koster-Dreese gave us a choice of how to use the knowledge of expected defects. One can try to prevent susceptibility to illnesses or defects, or one can equip oneself "against that which can be foreseen. . . "*

Third Session

A dynamic begun in the afternoon was magnified in the evening session, as Judy Heumann and Theresia Degener stimulated discussion of increased consumer involvement in decisions related to the use of technology and resource allocation. I learned that there appears to be a real and present danger in West Germany of returning to compulsory eugenic and preventive objectives through genetic engineering. The response of the group to Theresia's report was shock and anger, which was translated into action steps to mobilize the disability community.

Fourth Session

The tension of the evening session carried over into the morning, when Yolan Koster-Dreese gave us a choice of how to use the knowledge of expected defects. One can try to *prevent* susceptibility to illnesses or defects, or one can *equip* oneself "against that which can be foreseen, so enabling you to take the right measures at an early stage to begin an adequate treatment and start developing that part of the body and personality which will not be changed. . .and to train the part which will be damaged in such a way that it can deal with the defect." In her presentation, Koster-Dreese exposed the basis for the vehemence of the evening's session and foreshadowed the crescendo of the Symposium.

Koster-Dreese predicted that as the number of children born with defects in our society decreases, due to preventive technologies, parents who have children with disabilities will be blamed for not preventing the birth of an infant known to be "defective." She noted, "with some bitterness," that in such a society, she would be forced to demonstrate the quality of her own existence "in order to make this life attractive as an option for others."

In the discussion that ensued, the statement was made that if sperm banks are tolerated, genomes of persons with disabilities should be included. Irving Zola reacted quietly, but decisively. "I am not against technologies that could eliminate the cause of disability. There are limitations to disability pride." Yet another laser beam.

"Ethics is the logic of tragedy," he said. "No one can leave an ethical dilemma feeling happy. It wouldn't be an ethical dilemma without some loss of good or gain of evil."

Crescendo

The final session had a rather innocuous title: Health and Rehabilitation Decision Groups, Case Histories. Five minutes into the presentation by Robert Menter from Craig Hospital, however, the tension that had been building throughout other sessions reached a peak. Dr. Menter had prepared a video tape in which he and a psychologist had attempted to develop a process to deal with ethical dilemmas. Dr. Menter and the psychologist were shown in a retrospective discussion of the decision making process and subsequent death of a man with a high level spinal cord injury who wanted to die. The purpose was to explicate the process of honoring patient autonomy while preserving beneficience as an equally important ethical principle.

Dr. Menter turned his back to the audience throughout the 30 minute playback period. I thought I understood that rather unusual approach, (particularly unusual as the audience became more and more vocal in their disapproval), because I have also had the experience of videotaping a very personal experience and reliving it each time it is played for classes. I was aware of Dr. Menter's pain, his continued involvement in the life and death of his patient, and I suffered with him as the tape played.

The reaction from the audience, in my opinion, was not so much to the content of the video, but the way in which the professionals presented themselves. The clinical nature of the discussion and its message of dominance contradicted the intended message of respect for patient autonomy. I wondered, and still do, if Dr. Menter heard the sighs and thumps of disapproval, or if he was so absorbed in his own pain of reliving the process that he was not sensing the reaction.

I recognized the clinical detachment in the videotaped discussion as personal protection, for I have taught in a medical school and have seen physicians separate themselves from immediacy and the patient, a defensive response. I knew that many physicians protect themselves from the emotional consequences of medical practice in the hope of giving patients the best possible care (and preventing their own burn-out). But the unintended consequence of the detachment we were watching was to feed the outrage that had begun during the previous evening. My pain at this point was so great I could hardly breathe.

Fortuitously, Dr. Menter called upon Frederick Abrams to react to the presentation. Dr. Abrams had attended the evening session and had heard the audience reaction. His first statement allowed me to breathe again. "Ethics is the logic of tragedy," he said. "No one can leave an ethical dilemma feeling happy. It wouldn't be an ethical dilemma without some loss of good or gain of evil." For a moment this intellectual olive branch gave me hope that the impending catastrophe could be averted. Retracing some of the decisions made, Abrams pointed out the conflicting ethics of beneficience and autonomy, saying that the Hastings report on Ethical and Policy Issues in Rehabilitation Medicine (Caplan, et al, 1987) had ruled against "weak paternalism" (not immediately acceding to a patient's wish to die, without satisfying self of patient's awareness of the consequences). The Craig response was an excellent model, Abrams felt, as staff was able to follow their own conscience and were not required to work with the patient, once his decision to die was honored. "Competence is informed consent," Abrams said, "comprised of the ability to comprehend and consider information, to correlate it with life prior to accident, and to communicate."

The discussion began rather quietly, with Adrienne Asch asking more laser beam questions:

Where were other patients who maintained quality of life while on a respirator?

What opportunities did this man have to discover ways to use his forceful personality outside the hospital?

What opportunity did he have to think how he could be father to his children?

What is competence about, if it's not accompanied with powerful evidence of successful life after paralysis?

Those who had been waiting to respond now increased the tempo with a series of closed questions. "How many persons on respirators, living and working in the community did the patient meet?" An interrogation began; my pain increased. I had experienced the death of my mother, without the support of a physician in her bedroom of our house. One of the most accusatory questions was "Why not let him go home to die?" I knew what it was like to be at home, when dying stretches over 26 hours, without a physician. Dr. Menter *had been there*, perhaps not perfectly, but he had involved himself in the last and most personal life experience of another human being. I believe he had been deeply affected by the shared experience, exhibited great courage in making and replaying the video, and could not have anticipated the fire storm the video produced. The wounds of those closing moments remain open for me.

Conclusion

Ernlé Young believes that people of good faith will proceed to find solutions. Is this a false hope? Is Robert Slater's dream of turning confrontation into debate and democratic decision making beyond our ken? It seemed so in those moments of inquisition.

I returned to my work as a rehabilitation educator. A student dropped by and gave me David Hilfiker's book, saying: "You'll like this." The healing I needed has begun to occur, and Hilfiker's (1987) book has been a tincture. In his last chapter, describing his near exodus from the practice of medicine and what he has discovered from that painful journey, Hilfiker writes:

> *"Only by recognizing and accepting his or her own wounds can the healer minister to others. It is our wounds that make us human, that bridge the gap between patient and physician. When we have done all we can to improve our situation, when we have created the best environment possible, there will still be the pain that comes from meeting others deeply. At that point we can either fight against the pain, and in so fighting, bring ourselves to a numb cynicism or a fragile despair, or we can accept it, become one with it, and allow it to minister to others."* (p. 207)

We met each other deeply, in the process of the Sympsium. I wonder if others are fighting against the pain that last session produced. Numb cynicism or fragile despair seem possible consequences. For several weeks I fought despair. It is much more difficult to become one with the pain and continue to dialogue.

When we meet again, let us make war on mistaken thinking, not mistaken people.

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Theories and Values:
Ethics and Contrasting Perspectives on Disability

*by **Harlan Hahn**, Ph.D., University of Southern California*

> *The sharp conflict between health professionals and persons with disabilities that emerged during the symposium seemed to reflect the complex interaction between intellectual, personal, and ethical issues as well as the formidable problem of securing a hearing for new ideas.*

The sharp conflict between health professionals and persons with disabilities that emerged during the symposium sponsored by Rehabilitation International, the World Institute on Disability, and the World Rehabilitation Fund at the 1989 annual meeting of the Society for Disability Studies in Denver, Colorado, seemed to reflect the complex interaction between intellectual, personal, and ethical issues as well as the formidable problem of securing a hearing for new ideas. The controversy essentially revolved about divergent perceptions of the amount of attention to be focused on the contrasting theoretical implications of the "minority-group" and the "functional-limitations" models which have been struggling to gain ascendancy as the dominant paradigm for the study of disability. That normative and empirical concerns cannot be totally separated is indicated by the fact that each of these orientations is based on ethical values derived from dissimilar personal experiences. Moreover, since the traditional "functional-limitations" model, which has provided a theoretical foundation for research in medicine and rehabilitation, is more familiar than the relatively recent "minority-group" model, this analysis examines life-or-death questions from the perspective of a disabled person who has chosen to identify with the disability-rights movement and from the vantage point of the "minority-group" paradigm.

Functional Limitations Model

From the perspective of the "functional-limitations" model, disability is located within the individual. As a result, public attitudes and the stigma imposed by others upon disabled women and men are excluded from consideration. It is assumed that the benevolent desire to help or to improve the condition of disabled persons exhausts the conscious or unconscious feelings that professionals or others may harbor toward disability. No attention is devoted to the possibility that the external influence of negative perceptions is the primary source of the problems which people with disabilities encounter.

Hence neither is there any mention of the unfavorable attitudes that have made disabled women and men a deprived and disadvantaged minority facing one of the highest rates of poverty, unemployment, and welfare dependency as well as a pattern of segregation in education, transportation, housing, and public accommodations that parallels the practice of apartheid. These are the problems which must be solved to enable disabled people to lead a satisfying life; but the assumption that disability resides in the individual and the corresponding tendency to exclude exterior considerations from the field of analysis have prevented investigators from engaging in a

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In the immediate aftermath of a disability, for example, people are required to grapple with two of the most difficult questions that can be posed to any human being; namely, why? and why me? Answers obviously vary but one consequence seems certain: after a disability, people experience the world differently. And that difference is a source of creativity which can become the basis for empowerment.

serious examination of the ethical implications of these issues.

No one has openly suggested that children or adults should be exterminated in modern times because of the difficulties which they may confront on the basis of skin color, gender, or sexual preference; but these recommendations have been widely accepted with regard to individuals with disabilities. Even though relatively few persons are able to achieve an ideal level of physical functioning, limitations labeled as disabilities have been viewed from this perspective as pathological conditions to be eradicated or remedied to the maximum extent possible. Rather these limitations could be viewed simply as additional manifestations of the diversity of human attributes which may become a source of prejudice in a culture that imposes a high degree of conformity on the characteristics of its members. And little consideration is given to the possibility that professionals working with disabled persons might share some of the negative attitudes about disability pervasive in society or that their feelings may be influenced by the failure of their intervention to restore such individuals to a desired level of functional capacities.

Disability as a Source of Dignity

The "functional-limitations" paradigm seems to imply that the only means of adjusting to a disability involve prevention, which suggest the futile hope that such differences might eventually be abolished; normalization, or the effort to approximate the state of the nondisabled majority; and dissociation, or the attempt to reduce the importance of disability on a person's life. No provision is made for the possibility that some disabled women and men might actually wish to identify with disability as a source of dignity and pride. The ethical principles derived from the "functional-limitations" model reflect the faulty premise that all disabled persons would wish to eliminate their disabilities and that no one might conceivably choose to live with a disability as a matter of preference.

Perhaps most significantly, this orientation promotes a total denial of the positive experience to be gained from life with a disability. It tends to reject alternative personal values that can be fully realized when the penalties of social discrimination have been abolished. In the immediate aftermath of a disability, for example, people are required to grapple with two of the most difficult questions that can be posed to any human being; namely, why? and why me? Answers obviously vary but one consequence seems certain: after a disability, people experience the world differently. And that difference is a source of creativity which can become the basis for empowerment.

Furthermore, these individuals have an unusual opportunity to join the disability rights movement in an historic struggle to extend and expand the definition of human rights, which can provide an invaluable sense of meaning and purpose in life. As a result, it is imperative both that newly disabled citizens should have an opportunity to learn about these and similar perspectives derived from the lived experience

The conclusion seems inescapable that the reluctance of these professionals to consider values supported by the disability-rights movement can be ascribed to pervasive public fears and negative feelings about disability.

The "minority-group" paradigm is based on a socio-political definition of disability as a product of the interaction between the individual and the environment.

of other disabled adults and that theoretical assumptions should not permit nondisabled professionals to ignore such alternatives. Moreover, the conclusion seems inescapable that the reluctance of these professionals to consider values supported by the disability-rights movement can be ascribed to pervasive public fears and negative feelings about disability. Hence by neglecting these viewpoints and by suggesting that death could be an appropriate solution to the problem of disability, these professionals appear to convey an oblique and almost imperceptible but terrifying message about prevalent conscious or unconscious feelings concerning the remainder of the disabled community. Consequently, many disabled women and men fear that one possible solution to the problems posed by disability might eventually become *the* solution to the problem.

Minority-Group Paradigm

By contrast, the "minority-group" paradigm is based on a socio-political definition of disability as a product of the interaction between the individual and the environment. From this perspective, the principal difficulties confronting many persons can be traced to the exterior force of a disabling environment, which imposes severe restrictions on various types of abilities, rather than to supposed personal defects or deficiencies. Fundamentally these external influences reflect social attitudes that have shaped public policies which, in turn, determine both the physical capacities required to master the built environment and the segregating barriers imposed on various segments of the population.

The "minority-group" perspective is predicated on the belief that prejudicial attitudes can be altered primarily through the modification of institutions and behavior to facilitate equal-status contacts between disadvantaged and dominant portions of society. As a result, the inequality of the disabled minority can be remedied principally through legal and political action. Perhaps most significantly, this orientation points out that disabled citizens are exactly what the term implies: a minority group. Women and men with disabilities might appear to lack both a subcultural heritage and a sense of generational continuity, but they share with other oppressed minorities a realistic fear that the narcissistic propensities of the dominant majority to favor the predominant appearance of people like themselves could prompt a corresponding drive to eliminate the presence of others with deviant or supposedly undesirable physical characteristics.

From the vantage point of the "minority-group" model, therefore, the ethical values represented by the suggestion that death could conceivably be an appropriate solution to the problem of disability may be interpreted as a step toward genocide, or the eventual elimination of people who are designated as different from the majority of the population.

From the vantage point of the "minority-group" model, therefore, the ethical values represented by the suggestion that death could conceivably be an appropriate solution to the problem of disability may be interpreted as a step toward genocide. . .

Conflicts from Opposing Paradigms

Hence the emotional conflict over the notion that physicians might assist in the suicide of a newly-disabled citizen becomes understandable in the context of the radically dissimilar ethical implications of the opposing theoretical paradigms. From the viewpoint of nondisabled health professionals who have never had any personal or educational exposure to the positive values of life with a disability, death could be mistakenly treated as a supposedly humane option to the underlying frustration engendered when all of their techniques for restoring the functional abilities of the individual have been exhausted. By contrast, for many of those who believe that people with disabilities form a disadvantaged minority group, the danger of genocide only comprises the most extreme manifestation of aversion based on public attitudes that reflect the tendency to shun and to segregate those who are perceived as different.

Even though the precise basis of the egocentric proclivity of the dominant majority to prefer persons who are similar to themselves and to avoid others on the basis of skin color, gender, age, or disability has not been fully discovered as yet, such an explanation is not necessary to comprehend the justifiable fear experienced by women and men who have chosen to identify with their disabilities, the very trait that some members of the nondisabled group may be seeking to eliminate. Thus personal and theoretical concerns are joined in the position of many disabled people that regards the idea of death as a plausible response to disability as both morally reprehensible and personally threatening.

Need to Modify Educational Curricula

The "minority-group" perspective, which is founded on the lived experiences of disabled adults as well as on research in the social sciences instead of clinical disciplines, encompasses ethical values that cannot be totally ignored by health professionals and others in vocations that involve extensive work with disabled clients. Although these issues may be less familiar to researchers responsible for training students in these careers than other topics, a lack of knowledge cannot be considered an adequate excuse for the failure to assess the moral ramifications of this new approach.

In fact, there is a pressing need to modify educational curricula to acquaint students preparing for these occupations with the ethical dimensions of the "minority-group" paradigm and perhaps even to enable them to enhance their clinical skills by preparing for roles as advocates and monitors of laws protecting the civil rights of people with disabilities. Eventually this new orientation might even modify the relationship between clients and professionals by making them joint participants in the social as well as the personal struggle to improve the lives of people with disabilities.

There is a pressing need to modify educational curricula to acquaint students preparing for these occupations with the ethical dimensions of the "minority-group" paradigm. . .

At this moment in the history of the disability-rights movement and the development of public policy, however, major priority might appropriately be assigned to the development of an expanded dialogue about the moral principles embedded in these contrasting theoretical perspectives. And perhaps the most crucial prerequisite for this sort of increased discussion is for professionals trained in traditional clinical disciplines to display an increased recognition of—and respect for—the ethical values implied by the "minority-group" paradigm.

Current Example of Ethical Dilemma

This current example of a U.S. court case illustrates how an ethical dilemma can begin as a "live or die" situation defined by the medical system and can be redefined to focus on the availability of independent living and support services for people with severe disabilities.

IN SEARCH OF INDEPENDENCE

Quadriplegic pleads for centers for disabled

By Susan Laccetti
Staff writer

Johnny Crawford/Staff

Dr. Ross Fine holds the microphone for Larry McAfee during the Senate session.

> *"You cannot give us back our arms and our legs, our bladders and our bowels, but you can help us regain a tiny bit of our freedom and our dignity."*
>
> **Larry McAfee**

Quadriplegic Larry McAfee, who last year went to court for the right to die, pleaded with state lawmakers Wednesday to establish independent living centers for the disabled — a cry that may be answered in the state budget.

"I plead for an opportunity to live whatever time I have left with some semblance of dignity, self-respect and self-determination," the 34-year-old said, swallowing hard and choking on words during his 12-minute talk to the Senate.

"You cannot give us back our arms and our legs, our bladders and our bowels, but you can help us regain a tiny bit of our freedom and our dignity," he said.

Mr. McAfee now lives in an Alabama nursing home because there is no facility in Georgia equipped to give him an independent lifestyle. He was paralyzed from the chin down in 1985 as a result of a motorcycle accident.

However, Mr. McAfee may get the opportunity to return to Georgia if the House version of the fiscal 1991 budget becomes law. The House proposal, now before the Senate, contains $27,000 to house three disabled patients in a Dublin group home, according to Rep. Terry Coleman (D-Eastman), a member of the House Appropriations Committee.

Mr. McAfee drew national attention last year when he declared that he would rather die than remain dependent on others.

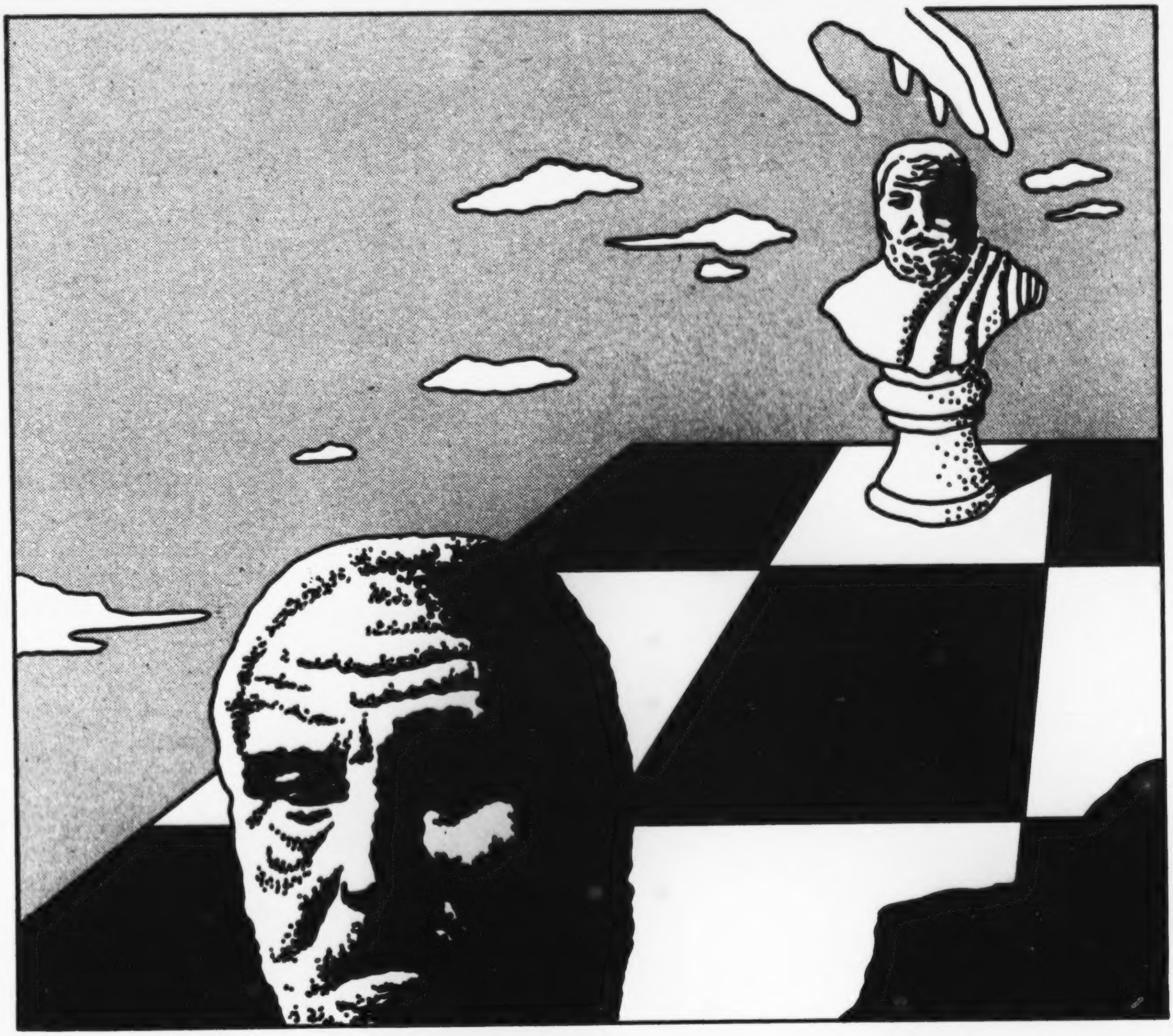
A Fulton County Superior Court judge ruled that he could turn off the respirator that keeps him alive, and the Georgia Supreme Court affirmed the decision.

While in Alabama, Mr. McAfee has became interested in computers and other advanced technology, which contributed to his decision to stay alive.

"He has taken that tremendous frustration, which I certainly understand, and channeled it into a positive activity," said Secretary of State Max Cleland a triple amputee who met with Mr. McAfee after his talk. "Anytime you have a disability and go before the public, I think that is pretty courageous."

Reprinted from *Atlanta Constitution*, February 22, 1990

Section 4
Selected Additional Papers



Drawing by Jeff Lindenmuth, *American Medical News*, January 2, 1987

High-tech Medicine Is Basic Care

*by **Frederick R. Abrams**, M.D., Chairman, Colorado Health Decisions Project*

Fifty years ago, my friend and teammate "Joey" became sick. When he came back to school, Joey couldn't play shortstop any more because he didn't walk—he lurched. I saw metal braces fastened to the tops of his ugly brown shoes. Polio became terribly real. I was 10 years old and afraid of summer.

No on knew where polio came from or how to avoid it. Mom made us wash our hands over and over, and the municipal swimming pools closed when polio cases appeared. Summer camps were closed or, worse, quarantined if an outbreak occurred there, with all the kinds waiting to see who was next.

> *"The allocation of scarce resources" is a phrase which rings in our ears daily. It leaves so much open to interpretation that it cannot go unqualified.*

The Fox Movietone newsreels showed people in iron lungs, which to us looked like the sarcophagi we learned about in history class, except they were open at one end. A head stuck out, and a person standing behind could talk to a reflection in a mirror. They were heroes, the people in the iron lungs. They survived. More than that, one lady took a paintbrush in her mouth and made beautiful pictures. We wondered how she went to the bathroom. All the newsreels showed how cheerful and courageous the polio victims were. Sometimes the lights in the movies came up, and boxes were passed across the rows so we could contribute to the March of Dimes to buy iron lungs or braces. Then our idol, President Franklin Delano Roosevelt, came on. He also was a hero. No one considered for a moment that the victims in iron lungs were using resources which could be used better by some other people who were sick, or by some other part of the economy which needed bolstering.

My childhood impressions of polio influenced my choice of a medical career.

Roots of "Rescue" Medicine

I do not know what experiences or genes strengthen the sympathetic vibrations we share—the awareness of our common humanity and our vulnerability. But I do know we are gregarious, and empathy abounds. This characteristic is what gives rise to the phenomenon of the "identified patient"—one whose condition qualifies him for a special lifesaving procedure. It makes a president send his airplane to carry a liver for a child's transplant, or a nation sit glued to the television until a baby is rescued from a well.

We each crave acknowledgment of our presence and our individuality. In a world of enlarging populations and depersonalization, we need to affirm our unique value and be reassured constantly that we are loved and appreciated. This is done through many groups: religious affiliations, cults, social clubs, family groups, dog and cat lovers, Harley-Davidson owners. From the ridiculous to the sublime, all contrive to help us belong. And this, I believe, it at the root of our motley health-care system, our national schizophrenia which inefficiently pours most of its public funds into rescue medicine and little into prevention. It is a system which the public, by a large majority, wants broadened, but fewer appear willing to be taxed to support it. It pressures physicians to be gatekeepers, or guards lest patients find their way in the health-care maze and deplete resources, yet exalts the high-tech medicine which uses the resources.

What Is Scarce?

"The allocation of scarce resources" is a phrase which rings in our ears daily. It leaves

Not all of us would choose to survive an injury which left us paralyzed and dependent on a respirator. But for those who choose to respond to this challenge, ought we not recognize such persons as prime examples of the indomitable human will, the very essence of the spiritual possibilities for humankind?

so much open to interpretation that it cannot go unqualified. Some things are genuinely scarce. Currently, organs for transplant are in that category. We may, through education, increase the supply, but it is quite possible that we always may have a shortage. The challenge becomes one of true distributive justice, a principle on which most bioethics texts and many papers have dwelt exhaustively, if not conclusively.

Other resources, however, are scarce by choice—by political choice. I question it because of personal experiences which moved me in the way people are moved by a child in need of a marrow transplant. We are beginning to define Dr. Charles Fried's "basic decent minimum" and the presidential commission's "Adequate Level of Care Without Excessive Burdens" at a level which the public has stated in poll after poll is insufficient. No one, the public says, who wants care should be denied critical or lifesaving care because of inability to pay.

What Is Basic?

What could be more basic than saving the life of someone—someone who finds the resulting quality of life, albeit diminished, nevertheless acceptable? When we talk about decent minimum, are we led to think this means minimum *cost?* When we talk about "basic," are we led to think this means *inexpensive?*

Not long ago, I attended a conference concerning high quadriplegia—quadriplegics for whom respiratory assistance was needed around-the-clock. These people could not breathe without pneumobelts, phrenic pacers, or portable respirators. Only a few decades ago, they would not have lived long enough after a high spinal injury to reach the hospital. Technology has created another class of patients to add to those who are alive because of dialysis or intravenous feeding. The average first-year cost for a high quadriplegic is $300,000, and annual maintenance averages $100,000. Here comes the heresy: I maintain this is "basic care"!

We speak much of ideals and virtues. Not all of us would choose to survive an injury which left us paralyzed and dependent on a respirator. But for those who choose to respond to this challenge, ought we not recognize such persons as prime examples of the indomitable human will, the very essence of the spiritual possibilities for humankind? Without glorifying the spiritual at the expense of the sensual, ought we not cherish them as symbols, as examples of the values which remain to be experienced in our culture which has leaned so heavily toward the materialistic?

One of these remarkable persons whom I met has transcended the injury she sustained at age 16, has completed law school and now practices law. She needs attendance virtually 24 hours per day for her needs, yet after a few minutes of conversation, her wheelchair "disappears." The bobbing motion she uses to activate the respirator knob with her chin becomes as natural as breathing. It is only later, during reflection, that one realizes how significantly such persons help the ablebodied around them.

For those who say we must choose between worthwhile preventive measures such as immunizations and prenatal care and high-tech rescue interventions such as transplants and high-quad respirators, I say no. We must not!

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high-quad respirators, I say no. We must not! Certainly we need to maintain our country's infrastructure, education, and even defense, but for whom do we maintain them? We do not maintain them only for the healthy or those who can buy high-tech interventions privately. Almost no individual can afford the costs for high-quad intervention and maintenance. But who uses the bridges and roads, the colleges and factories? As we all pass beyond the fantasy of immortality and invulnerability of youth, we hear over and over again how health is at the top of the necessities list. Given a defined sum to spend on health care, we certainly will have to set priorities. How high shall we set the defined sum? We clearly are showing in our Medicaid programs that we are not allocating sufficient funds now or making them accessibly to all those in need.

Let's cut waste, inefficiency, duplication—the legendary "fat" of health systems. Let us not force care on anyone who does not desire it. Let patients choose or refuse care based on their own assessment of life's quality.

Let us face the fact that medicine's technical success, more than greed and waste, shares the blame for our dilemma. Like any expensive but desirable product, the society which demands it must pay for it by sacrificing other goods. The people have declared repeatedly how high a priority they give health care. If they are informed and if they participate in structuring the tax burden and the distribution of health benefits, I believe they will be willing to pay for that which they appear to value highly if they perceive they have been treated fairly. A nation which spends four billion dollars annually on potato chips can provide its citizens with a high level of medical care.

Prevention of Disabilities as a Medical Question

Presented to the joint meeting of Rehabilitation International's Medical and Social commissions, October 21, 1989, Toledo, Spain

by G. Schioler, MD, DPH, Deputy Director General, Danish National Board of Health

My background for speaking about this topic is my work: first 12 years in the clinical activities mostly in orthopaedic surgery, and the last 13 years in the Danish National Board of Health. In this period, I have been constantly involved in the Board's advisory functions within both curative and preventive medicine. Our counselling is first and foremost to the Government, but also to the Parliament and local health authorities, and—not to forget—to the public.

From my senior post I have observed that during the 80's, the political discussion on health policies has focused more and more on the importance of prevention and the improvement of quality of life. No doubt, the activities of the World Health Organization (WHO)—and many non-governmental organizations—have had an influence on this development—if not, in fact, caused it!

Strangely enough, the changed objectives of the political discussion in some cases have led to an almost hostile attitude towards the medical profession as such, and especially towards highly specialized groups within the curative health services. Some lay people—of course including some politicians—have acted as if it is possible to prevent almost any disease—and even do it without the medical and scientific knowledge we have gained through the last century or two. In many cases I have seen the medical profession taken by surprise by such discussions, and many highly competent doctors have been brought into a more or less defensive position. Maybe this is not so strange.

After all, doctors for centuries have been educated to treat and hopefully also cure the diseases of their fellow citizens. And diseases have been—and by many people still are—considered as something unavoidable in the natural course of a human life. To cure or at least relieve such conditions and their impact on the individual person has been the doctors' living, and they have not really been taught to remove the very basis of their own existence—and could I add, the basis for their powerful position in society.

I have observed that during the 80's, the political discussion on health policies has focused more and more on the importance of prevention and the improvement of quality of life.

So it has been, and to some extent, still is. Not until the last few decades has prevention moved in as an integrated part of the individual doctor's training and professional duties. But now we have not only reached a stage where we have the knowledge and mastery of technologies to prevent or detect very early a lot of diseases: we also have reached a stage where prevention is accepted as an important component in the health service.

I admit that for many colleagues prevention is not yet as prestigious as open-heart surgery, but prevention has surely got its platform in the medical universe. It is true for prevention in general, and it is certainly true for prevention of disabilities caused by diseases, accidents and inborn disorders. And that is my topic today.

Prevention: A Medical Question

To me, there is no doubt that prevention is a medical question. Or should I rather say: it is *also* a *medical* question. This is more correct, because the medical part of prevention is some of it, a large part of it, but it is not all of it. That is why we are having this joint meeting, and why we could and maybe should, consider together to hold other joint meetings with people from other sectors of the community such as education, traffic, industry, etc. Today, however, I must concentrate on the medical aspects—and the questions this raises for the doctors and for all others with responsibilities within the medical services.

Example of Diabetes

Let me take an example of some significance, and to me, very illustrative! Last week I attended a WHO meeting in Italy on the topic "Diabetes in Europe—a model for prevention and self-care". As we all know, a diabetic person can live a normal, active life, and today it is a question whether we are allowed to call a diabetic a disabled person. But it is also well known that a diabetic person constantly lives with the threat of severe complications, which can lead to disabilities such as blindness and amputations. This threat can only be efficiently reduced through qualified and sufficient medical care.

At the end of the meeting, we made some recommendations to the European countries which, among other good advice, also included the following five year targets:

1. Reduce blindness due to diabetes by one third or more

2. Reduce the rate of limb amputations for diabetic gangrene by 50 percent

3. Reduce the number of people entering and end-stage diabetic renal failure by at least one third

Somebody here may be surprised that setting-up such targets is relevant to the well-functioning European health services, but I can tell you that they are!

Out of the 10 million diabetic persons in Europe, too many develop complications, which can be prevented or significantly postponed, if the medical profession can and will meet the problems with efficiency and engagement. The doctors must take a leading role in the professional teams that are a prerequisite for real and effective prevention of the disabling complications to diabetes.

The medical care for diabetic patients clearly shows the need for the preventative approach in the lifelong treatment of chronic diseases. I will not elaborate further on this, the medical challenge is obvious, but say a few words on another important function related to the acute health services.

Accident Prevention

The medical profession must be constantly aware of accidents as a very common cause for disability, and too often causing severe disabilities, which in one moment can change totally the life of an active person. Correct and specialized acute treatment in many cases will be of crucial importance, if disabling complications shall be prevented or diminished. In most countries we can do better than we do now, and it is our responsibility that improvements are made.

However, the medical responsibility in prevention of disabilities caused by accidents goes much further than that. We must work actively in the prevention of accidents as such. We must study and analyze the types and patterns of accidents and the lesions caused by them. We must convey our findings to those, who can do something to change our roads, our cars, our production, and to those, who can improve the health education in the schools and so on. Such a qualified and well documented medical input in accident prevention is essential for the success of our total efforts.

New Diagnostic Technologies

Prevention as I have discussed it until now, does not create many problems. It is for most people a natural thing to prevent complications of chronic disease and to decrease the number of accidents as much as possible. But, out possibilities are not limited to this!

Today, diagnostic technologies make it possible to detect several diseases or disorders as

> *As doctors we must understand and be ready to discuss the consequences of knowing that a fetus is "abnormal", whatever that is.*

early as in the 10th or 12th week of pregnancy, and ultrasound scanning used by skilled personnel can detect disabilities long before the fetus will be born as a child with a disability. For the medical profession this fact opens up for new and quite different problems.

As doctors we must understand and be ready to discuss the consequences of knowing that a fetus is "abnormal", whatever that is. Abortion is in many cases a natural solution, but it is not the medical profession or the community, who can decide whether a given pregnancy should be terminated with an abortion or not. This decision rests only with the pregnant woman and her family. Depending on cultural, religious and social background, the ethical and emotional aspects will be quite different from case to case. And so will be the decision. And probably, it will not be a rational decision from the doctor's viewpoint.

I could also put it another way. The fact that the doctor is providing the diagnosis of the fetus cannot be a reason for, or in any way justify, that the doctor takes over the decision on the consequences for a patient. But he must be the good and professional counsellor, who can support his patient in reaching the decision which is best for her. It is the patient, not the doctor, who is going to live with the consequences!

Mostly this does not create problems, either to the patient or to the doctor, so why bring it up here? For at least one good reason. In a very near future we will be able not only to detect disorders in the very young fetus, we will also be able to find carriers of inheritable diseases. For cystic fibrosis it is already possible, and in a few years it will be both technically and economically within the reach of many countries to include screening for carriers of this and other genetic disorders in general health programs.

Sensitive Social Issues

But is this what we have to do with such scientific achievements? Personally, I am not quite sure, and a few questions, really very simple questions, may help you to understand why.

1. In a family, one of the parents is a carrier of cystic fibrosis. They will never have a child with the disease, but one or more children will be carriers. We can find out early in pregnancy. Shall our ideas of prevention go as far as to prevent the existence of carriers of genetic diseases?

2. If one of the parents has the disease which will make all children carriers, what then?

I, myself, don't have a final answer, and certainly, it will be still more difficult when carriers of several more diseases can be revealed. Will we end up with a crude public opinion, which doesn't allow families to have children with inheritable diseases, or maybe not even have a child who is a carrier of such a disease?

> *. . .in a few years it will be both technically and economically within the reach of many countries to include screening for carriers of this and other genetic disorders in general health programs.*

Ghosts in Clear Daylight?

Is this to see ghosts in clear daylight? I don't think so, and if anybody is able to deny the existence of such risks, they can only base such a denial on hope. What has happened around the world in this century gives no reason to base the denial of the risks on facts.

Therefore, it must be our professional duty to be aware of these problems and unanswered questions, and to discuss them openly between colleagues and with the interested communities around us.

I want to emphasize that these very delicate ethical questions always must be dealt with within the cultural and religious framework of a given society. It is not possible to set up general rules for global use.

Added to this, I want to emphasize that these very delicate ethical questions always must be dealt with within the cultural and religious framework of a given society. It is not possible to set up general rules for global use. I think that everybody can agree on that.

Danish Experience

In Denmark we have seen what I think is a quite unique result of the public debate. About two years ago, our Parliament passed a law which established an independent Ethical Council under the Minister of Health. This council has two main functions:

First: to advise the Minister and the Parliament on ethical aspects of new biomedical technologies and their use in treatment and prevention; and

Second: to ensure public awareness of this development and initiate public debate on the questions coming from it.

The Council has explicitly been given the obligation to work with problems related to the beginning of life, that is, new technologies in neonatology, prenatal diagnostics, in vitro fertilization, etc. This means that we have now a formal forum for handling also the ethical aspects of primary prevention of disabilities.

Our actual and especially our coming possibilities for primary prevention of congenital disorders directly touch the very reproduction process of the human race. This means that medical science moves into sacred grounds for most people in the world.

So far so good, but I myself don't feel that the establishing of our ethical council is a solution to anything. What we have seen of their work until now is far from convincing, but the fact that the Parliament has established such a Council shows to me that large non-professional groups have demonstrated a deep and serious concern about the achievements of medical science and technology, or rather, about the impact these achievements may have on daily life and the possibilities of the individual citizen and families.

The implications of primary prevention of disabilities is like war: it is too important to be left to the generals. But, like war, it will not be successful without the generals.

I am convinced that this phenomenon is not a local Danish process, neither is it a question of a short-lived fashion. In medical history, I cannot see any other period of time where medical activities have been so much discussed in the public as they are now, and I am not complaining. On the contrary. Our actual and especially our coming possibilities for primary prevention of congenital disorders directly touch the very reproduction process of the human race. This means that medical science moves into sacred grounds for most people in the world.

And being on sacred grounds means that the discussion and the necessary decisions cannot be only a medical matter. It must be a matter for all members of the society, but can and should not be handled without a qualified—and open-minded—input from the medical profession. The implications of primary prevention of disabilities is like war: it is too important to be left to the generals. But, like war, it will not be successful without the generals.

It is my hope that what I have said in this short presentation has given you some kind of a summary of prevention as a question of highest importance for the medical profession. It has been my intention to put some questions, which I find vital in the discussion, but it has not been my intention to present "golden" answers to this question. Hopefully, I have pushed some buttons in your minds and thereby given a contribution to a useful discussion today.

Thank you for your attention.

The Ethics of Disability Prevention: A Parent's Point of View

by Mrs. J. Baker, Faulconbridge, NSW, Australia,
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I would like to introduce you to my children, Paul, Mary, Kevin, Angeline, Jim and Penny. Without expensive neo-natal technology, three of these children would not be alive today. Mary was born blue in color, and not breathing. Revived, she continued to have blue turns, was weak and unresponsive. Kevin and Jim were robust little boys but within hours of birth developed the tell-tale jaundice indicative of toxicity caused by the blood disorder, Ab0 incompatibility. Within hours of birth, the need for technological intervention to ensure survival was evident for each of these children.

Science has presented us with scenarios unimaginable 25 years ago. Faced with the viability of life as early as 26 weeks gestation and the care needed to nourish that life through to independence, society now asks itself whether the effort of providing that sustaining care can be justified. That's where the "killing phrase" (and I use that term advisedly), that killing phrase "quality of life" comes in.

Kevin and Jim received exchange transfusions in their first twelve hours of life. The arrangements were made, I was given permission papers to sign and the transfusions were carried out in rapid succession. At no point did anyone formally ask me if I would consent to the transfusions. It was assumed that of course I would consent.

Twenty-four hours after Mary's birth, it was left to a nursing sister to tell me she had Down Syndrome—of which I was already aware—then later a pediatrician explained she had a heart defect which would probably need surgical intervention if she were to survive. With some awkwardness he asked if, given my understanding of her condition, I would be prepared to consent to a corrective operation. When I responded immediately that I would consent, he looked very relieved and said that I had made "a wise decision". Since for me there was no decision involved—it was my daughter's life in question—I was surprised at his attitude. He went on to say that many people believe that "when nature presents us with a problem, she also gives us a solution to that problem."

Kevin, Jim and Mary all were in life-threatening situations. Mary also faced a life with limited intellectual capacity. Severe Ab0 incompatibility untreated in time can cause mental retardation. Why then was the attitude to intervention in Mary's case so different to the attitude in the boys' situation? The answer has to be in what a third party believed to be an "unacceptable quality of life" for Mary. Successful exchange transfusions (even if the procedure had to be repeated a number of times) could prevent retardation for the boys. Corrective surgery could improve Mary's cardiac function, but would not alter the fact of her intellectual disability. Therefore, automatically the boys had the right to technological intervention to save their lives but Mary did not.

Science has presented us with scenarios unimaginable 25 years ago. Faced with the viability of life as early as 26 weeks gestation and the care needed to nourish that life through to independence, society now asks itself whether the effort of providing that sustaining care can be justified. That's where the "killing phrase" (and I use that term advisedly), that killing phrase "quality of life" comes in.

> *Who has the right to decide the choice of risk for the very premature or severely deformed baby? Is it his mother, his father, his pediatrician, the social worker or legislator?*

Some children are born so handicapped by virtue of prematurity or physical or intellectual deformity that they could be said to be "born dying". Medical intervention would only prolong that process of dying. Given all the care that humanity, law and international charter guarantees every human being, those children die and we grieve for their passing.

But there are other children born who require special care to encourage their life spark into full flame. These children are children "at risk". They are children whose prospects do not match up with someone else's view of an "acceptable quality of life". Their lives are not worth saving, so some say. Yet triple bypass cardiac surgery may be taken for granted.

Yes, it is true that substantial sums of dwindling national resources go to the provision of life-sustaining medical procedures.

Yes, it is true that many of those assisted to live do not subsequently have a life others of us would want to have.

And yes, it is true that some families cannot cope with their infant's disability and so abandon him to society's care, while others find the fabric of their own lives permanently altered as they incorporate their new baby into their family.

This is the wonderful twentieth century! We greet each new technological advance with delight—we accept as our right the wonders of the age. We are thankful that we live now and not in some other less sophisticated century. But there is a price—a price our fathers paid in their generation. That price is the acceptance of the responsibilities that accompany the benefits of our age.

If we are capable of saving the life of an "at risk" baby then we must—it is a measure of our degree of civilization. If we can, and do not, we are saying, "Yes, we want to live in the twentieth century, but we want to abrogate that responsibility for the protection of life that our fathers in more primitive times were strong enough to accept."

Let us look at the risks for the child for whom an "acceptable quality of life" is not anticipated. He may be denied corrective surgical intervention, his medically alleviable illness may not be treated, his life-giving ventilation and monitoring systems may be disconnected, he may be deprived of nutrition to the point of death by starvation and at the extreme he may even be denied liquid and sedated until he dies of thirst. This is happening in our hospitals now. Some are suggesting a lethal injection be accepted as a "humane" alternative to these options.

If these are the risks, who among us would like to face them in our own lives? Who has the right to decide the choice of risk for the very premature or severely deformed baby? Is it his mother, his father, his pediatrician, the social worker or legislator?

As Mary's mother, I tell you no one has the right to make that decision, to take that responsibility, not even his parents. That child is a human being, whose life is his own, whatever the quality of that life. Who are we, as no more than any other human being, to determine what is the future of that life. If any of us takes that responsibility upon himself, he is assuming an authority, a power to which he is not entitled by virtue of his own imperfections as a human being.

The premature or disabled infant is still an infant, a human being. As such, he is entitled to the fullest protection of the law and the support of every other member of the human race. He is entitled to life and the means to maintain it, food, shelter, family and education.

He is also entitled, by virtue of his disability, to something else, something that we here, and thousands like us, owe him. We owe him our advocacy.

The "quality of life" argument is dominated by those who do not know what it is like to be disabled, dominated by those for whom an acceptable quality of life is measured by material and social achievement.

The "quality of life" argument is dominated by those who do not know what it is like to be disabled, dominated by those for whom an acceptable quality of life is measured by material and social achievement. We who are disabled or who have disabled friends, family or workmates owe to those infants our affirmation of the value of their lives. It is for us to show the achievement of the disabled life but more importantly, the enriching contribution that life that can make to the community.

It is a great mistake to believe that one can only contribute to society in the active physical sense. After all, what we do in the office, the home, the factory is ephemeral, whether we do it as an able-bodied or disabled person. What counts is what the great philosophies and religions of the world are all agreed upon, and that is the spirit of man. It is this that gives worth to what is basically the daily grind.

It is not enough to say that in extinguishing the life of a blind infant we may be destroying a Milton or an Einstein in a deaf one. In extinguishing the life of any infant we are denying the world the contribution that infant can make simply by being alive, by laughing and loving, hurting and needing, simply being a human being.

We who are disabled or who have disabled friends, family or workmates owe to those infants our affirmation of the value of their lives. It is for us to show the achievement of the disabled life but more importantly, the enriching contribution that life that can make to the community.

It is an old image that society is a fabric rich in pattern and color. Those who argue that some do not have sufficient "quality of life" expectancy to be a thread in that fabric are destroying the fabric itself. If we allow this argument currency and do not take a stand against legislation incorporating it, we will end up with a society which has swapped its coat of many colors for the polyester business shirt.

And that, my friends, is what it's all about—the tailor-made society. If we do not have the courage to say that the child born living is entitled to such support and intervention as is necessary to maintain that life, we must accept the inevitable consequence of acquiescence in his death. If you read the literature, listen to the speakers on the "quality of life": you hear the classic case of anencephaly, followed by spina bifida, followed by Down Syndrome. We know that the anencephalic child is a child born dying, but the child born with spina bifida or with Down's Syndrome is capable of life and entitled to it. It is a very short step from the extinction of life for these to the extinction of life of those who do not meet the criteria of the genetic engineer. If we "prevent disability" at birth, we can certainly "prevent" other imperfections, like my freckles for instance. We could standardize people as easily as we standardize nuts and bolts.

It is an old image that society is a fabric rich in pattern and color. Those who argue that some do not have sufficient "quality of life" expectancy to be a thread in that fabric are destroying the fabric itself.

In 1985, Justice Michael Kirby called for "the stone to be lifted" on the subject of the prevention of disability at birth by the extinction of the life of the disabled infant. He made this plea so that a community consensus could be reached and guidelines laid down for the medical management of disabled newborn infants. It is for us to take an informed part in this discussion, a helpful part. It is for us to demonstrate that there is a future for the disabled child and his family. It is for us to provide the support and information needed by the child and his parents to help them come to terms with the realities of their situation. It is for us to ensure that the media is used to the advantage of the disabled and not to their detriment. And it is for us to ensure that those who have the power to make and influence decisions (doctors, sociologists and legislators) have a true understanding of the capacity of the disabled person to live and enjoy life.

That is what we owe our disabled friends, family and workmates—our affirmation of their humanity. And this is what we owe to society: to declare what the wise have always known, that for me to deny the humanity of another dehumanizes me.

A Reference Matrix for Issues of Life & Personhood

*by **Mike Miles**, Director, Mental Health Center, Peshawar, Northwestern Frontier Province, Pakistan*

Issues concerning fetal growth, birth, survival and the care of disabled children are debated usually within particular societal contexts with restricted ethical, philosophical and religious parameters. Debate often focusses on single issues or a small part of the spectrum of bioethical concerns. The limits are understandable, in that the propagation and care of infants is basic to human communities and people are most concerned with issues relevant to their own immediate society and function. To place the issues within a broader ethical context may, however, bring a useful clarity and perspective.

The present entry-level matrix provides a view of a larger bioethical field in which, too often, mini-debates have taken place without reference to neighboring issues.

Purpose of Matrix

The matrix (Figure 1), of 36 possible actions or policies in given situations relating to life and personhood, sketches a *continuum* of ethical decision-making. It has been used informally to give a framework for discussions with both medical professionals and laypeople.

In (A1), for example, a couple avoids conception without recourse to artificial devices, when they know there is a high risk of severe fetal defect. Their action would be permitted, even encouraged, by most PERILS (Philosophical, Ethical, Religious, Ideological or Legal Systems). It would be censured in a society where there is strong pressure to produce a male heir of normal ability, and where there is little concept of scientifically predetermined risk. In (J3) measures are taken to kill an apparently normal neonate. This would be condemned by most PERILS, yet occurs daily in regions where female babies are accorded small or negative value(1).

Most PERILS and individuals draw their lines of "right, wrong and doubtful" somewhere between (A1) and (J3). Medical professionals might wish to extend the matrix with further levels of severity of impairment, time periods in the "Abortion" category and grey areas for case-by-case decision. A matrix has some inherent drawbacks for displaying a continuum. By its nature it appears to segment the material, while in fact wherever the lines are drawn there will be transitional or cross-boundary cases. Using a matrix is no substitute for careful thinking, but it can aid rationality in areas that may be over-influenced by emotional reaction.

Societal Inconsistencies

The present entry-level matrix provides a view of a larger bioethical field in which, too often, mini-debates have taken place without reference to neighboring issues. It also assists the identification of issues common to all sectors, e.g. the question "To whom does a child belong?". Some advocates for contraception, abortion, infanticide or "ability apartheid" may assume in common the parents' or family's right to dispose of the child/fetus as a chattel. Some opponents may hold in common the belief that the child/fetus belongs first to a deity or to society as a guarantor of the child's right to live and flourish. Many societies display inconsistent or ambiguous attitudes towards this question, e.g. forbidding abortion and infanticide but thereafter exercising very little control over parents' actions towards their children. Other societies may freely permit contraception and abortion, taking the fetus lightly, but assume major responsibility once a child is born alive.

Figure 1
Reference Matrix

Contraception when:	**High risk of severe impairment**	**Enhanced risk of defect**	**Normal baby expected**
a) Natural methods, e.g. abstinence, rhythm	A1	A2	A3
b) Physical/chemical barrier, e.g. condom, ovulation inhibitor	B1	B2	B3
c) Action against fertilized ovum	C1	C2	C3
Induced Abortion when:	**Fetus severely impaired**	**Fetus with enhanced risk of defect**	**Fetus presumed normal**
d) Up to 13 weeks	D1	D2	D3
e) 14 to 25 weeks	E1	E2	E3
f) 26 weeks to term	F1	F2	F3
Infanticide when:	**Neonate severely impaired**	**Neonate mildly impaired**	**Neonate appears normal**
g) Withholding exceptional life-support care	G1	G2	G3
h) Withholding normal care (incl. normal medical and surgical treatment)	H1	H2	H3
j) Active measures to cause death	J1	J2	J3
"Ability Apartheid" when:	**Child severely impaired**	**Child mildly impaired**	**Child of normal ability**
k) Segregated social and educational provisions	K1	K2	K3
l) Institutionalization: life spent in "colony"	L1	L2	L3
m) Vegetablization: support of physical life with minimum stimulation	M1	M2	M3

> *Beyond the non-support or denial of physical life, a child's psycho-social life and personhood may be at risk from a policy of separate social and educational development on the basis of the child's perceived ability level.*

Beyond the non-support or denial of *physical* life, a child's psycho-social life and personhood may be at risk from a policy of separate social and educational development on the basis of the child's perceived ability level, (K1) to (M3). (*Separate development,* in this context, suggests the label "Ability Apartheid"). Such a policy may have good intent, e.g. that special care and a well-designed environment be provided to a child for whom standard facilities seem inappropriate. Segregated facilities for children with severe impairments (K1) were approved by most PERILS in the past and are a current goal in some Third World countries. However, advocates of normalization, like opponents of racial and sexual apartheid, have pointed out the danger that separate and different facilities easily become stigmatizing and prejudicial to the social and mental growth of participants. The mainstream may also be impoverished by the removal of 'difference'.

Notes to the Reference Matrix

(A 1-3)

(i) Knowledge of genetic risks is recent and imperfect.

(ii) Traditionally the major monotheistic religions taught that marriage required the intention to have and to nurture children, unless the couple were elderly. Avoidance of conception was permitted only as a temporary measure and by natural methods. If the couple did not wish to have further children, they must abstain from genital intercourse. The 'safety net' of abortion was forbidden, as was infanticide or 'neglect to death'.

(B 1-3), (C 1-3)

(i) Some differentiation may be made between (B) and (C) by those who define "life" to begin at the moment of fertilization rather than successful implantation, and who attach significance to the difference.

(ii) In the World Medical Association's Declaration of Geneva, a modern "Hippocratic Oath", doctors undertake to "maintain the utmost respect for human life from the time of conception..."

(D1) & (D2)

(i) In the first 13 weeks there can seldom be certainty of any defect in the fetus, though enhanced risk may be known. Scientific advances may bring (D1) into focus within a few years.

(ii) The original Hippocratic Oath(2), undertakes neither to give deadly medicine to anyone, nor to give a woman a pessary to produce abortion.

(iii) The World Medical Association's 1970 Statement on Therapeutic Abortion approves the performance of abortion "only as a therapeutic measure", and where it is legally permitted.

(E 1-3), (F 1-3)

(i) Legal systems that admit abortion vary in what is permitted between about 15 weeks and 28 weeks. Clear and meaningful distinctions within this period are not easy.

(ii) Premature neonates may survive, with exceptional care, from about the 24th week. After this date, procured abortion may more readily appear to deny an existing and viable human life.

(iii) It may be argued that the pregnant woman's health is at risk from the anxiety of knowing or believing that her baby has an impairment.

(iv) The major religions have traditionally opposed the procurement of abortion. Their opposition has retarded but by no means eliminated the practice. The past 25 years have seen some shift in public opinion and medical practice in some Western nations(3), towards accepting (D 2,3), (E 1-3) and (F 1,2). The idea that a baby unwanted by its parents would

Conflict is increasing over budget priorities, e.g. expenditure on life-support systems as opposed to other financial needs.

suffer a severely impoverished life, and might better not be born, carried weight in countries whose populations had grown used to increasing personal control over their life-circumstances. On the other hand, and perhaps for a similar reason, the same countries produced campaigners for children's rights.

(G 1-3)

(i) These situations arise only in modern hospitals, and (G2, C3) only when there is prematurity.

(ii) Conflict is increasing over budget priorities, e.g. expenditure on life-support systems as opposed to other financial needs. Life-support systems lead to increased survival of severely impaired babies, generating further demands for specialized services. Western societies have made little progress towards meeting these demands, and families with severely or profoundly handicapped members face many difficulties[4].

(iii) Autton [5] (p. 134f) presents evidence for and against some preliminary education of prospective parents so that, in case of crisis, they may more capably participate in decisions about the use of life-support technology. He also discusses (p. 141) a more sensitive preparation of parents for coming to terms with the death of their baby, detached from the paraphernalia of the intensive care unit.

(H 1-3), (J 1-3)

(i) (H1) and (H2) have given rise to legal cases in some Western countries recently and to debate about how severe a given impairment is, immediately and potentially, and whether it is ever reasonable to decide for a baby that it is "in her best interests" to die[6].

(ii) At present most PERILS condemn (H2), (H3) and (J 1-3), though (H1) may lead to a situation in which (J1) appears the lesser of two evils.

"Ability Apartheid"

(i) This section is a logical extension of the Contraception-Abortion-Infanticide matrix, because the avoidance or elimination of any of (A-J, 1,2) may later give rise to (K-M, 1,2).

(ii) Some PERILS and individuals who condemn or avoid the earlier actions may wish also to avoid the later situations arising. Others may argue that risk of the latter is sufficient reason to contemplate one of the earlier actions.

(iii) Adherents of religious sects sometimes keep children in such seclusion as to amount to "colony" institutionalization (L3). Children born in jail may be similarly restricted.

(iv) Societies vary greatly in their view of the rights of parents or guardians to control a child's life and liberty. Legal, or social sanctions may seldom need to be used against so bizarre a procedure as (M3)–yet cases are discovered occasionally of children, with or without impairment, who have been kept barely alive in a cage or cellar by mentally unbalanced adults.

It is no longer possible to define specific ethical positions unanimously and authoritatively taught by any major world religion or ideology.

Religious/Ideological Influences

It is no longer possible to define specific ethical positions unanimously and authoritatively taught by any major world religion or ideology. While 90% of humankind live in proximity to Christianity, Socialism, Islam, Secular Humanism, Buddhism, or Hinduism, none of these now has a universal recognized teaching authority. The ancient scriptures do not specifically address modern ethical issues. Broad principles perceived in those scriptures are variously interpreted and applied by believers. It is not in the nature of Hinduism or Buddhism to propagate law codes, though they are deeply concerned with life questions. The same is true of Humanism and Socialism.

While no longer making authoritative universal pronouncements, the major religions and ideologies still influence the terms and conduct of debate. Because of their position as regular users and custodians of the *language* of ethics and morality, they are likely to remain influential for the foreseeable future, even if religious belief and observance wanes or becomes more heterodox. Two trends may be noted: a) Convergence and Diversity; and b) Ignorance and Development

Convergence and Diversity

Convergence appears in the lofty ideals expressed on behalf of all the major religions and ideologies, desiring a life of full worth and dignity for all the human race. These ideals are not always helpful when practical decisions must be taken. The rights and dignity of one person may appear to conflict with those of another, e.g. the pregnant woman and her potential baby, or the impaired neonate and the family into which it is born.

Convergence of sentiment and ideal, exemplified in the widely subscribed declarations of the United Nations, hides some fundamental differences of perception and value. The Asian philosopher who states that "The quality and value of a low-birth-weight infant is lower than those of a normal infant"[7] and the Eastern physician remarking that "The general public tends to think of induced abortion much as constipated patients do of a purgative"[8], indicate a substantial gulf between Eastern and Western sentiments.

Asian religions and philosophies, holding variously to doctrines of reincarnation and the illusory nature of the "self" and of much ordinary human activity, naturally find values and life-meanings that differ from Western views deriving from Semitic monotheism and early Greek philosophy. "Quality of life" may be seen in the East as right conduct, mentality and intention; in the West, as security of possessions, abilities and a range of life-choices.

For example, a belief that one's body is merely the latest in a series of incarnations, bearing the soul onwards to a remote destiny, might appear to make to make life-or-death decisions less acute, compared with a belief that no individual has more than one physical life and body. Avoidance, non-support or denial of a particular infant or fetal body, removing its potential to carry a soul, should merely result in that soul being reincarnated in a different body rather than irrevocably stopping the cycle. However, beliefs in this area seldom proceed with such simple logic. If one aspect is less acute, other aspects will more than compensate in difficulty.

> *The rights and dignity of one person may appear to conflict with those of another, e.g. the pregnant woman and her potential baby, or the impaired neonate and the family into which it is born.*

Belief in reincarnation usually accompanies a belief that actions now will influence the next incarnation of the actor, that suffering now is a consequence of misdeeds in a previous incarnation and that such suffering may be a necessary preparation for the incarnation that follows. A doctor believing this may feel less incentive to intervene in the suffering of a severely impaired neonate and its family. Such an act could merely interfere with their destiny and put the doctor at risk of retribution in his next incarnation. The *range* of thoughts in this doctor's mind might not be so different from those of an atheist or monotheist colleague, but they may well be differently *centered*.

Ignorance and Development

Religious teachers, of whatever creed, tend to be poorly informed about modern bioethical issues, though some Western religious hierarchies have tried to keep up with scientific developments. A Buddhist commentator concedes that "such controversial questions as abortion...euthanasia, the right to die...are areas

"Development" in ethics is often feared as a one-way street down which religious teachers are dragged, making ever more concessions on principles such as the "sanctity of life".

that are not clearly defined in Buddhism and in other religions"[9]. Such an admission opens the way for learning, which may be facilitated by exposure to ethical views based on appreciably different foundations. Juergensmeyer[10], taking the ethical views of Mahatma Gandhi as an example, sees both an openness to change and a mutual convergence as being among the benefits of a 'global stance' in ethics.

"Development" in ethics is often feared as a one-way street down which religious teachers are dragged, making ever more concessions on principles such as the "sanctity of life". However, the general public has its own pace of accommodation to new viewpoints. Concerning abortion in Japan, an Asian doctor notes[11] that "after 15 years of this massive antepartum infanticide a section of public opinion is revolting against it, despite all the material wealth that the people may enjoy from the easing of population pressures." A similar swing of the opinion pendulum has occurred in some Western countries.

Religions associated with revealed scriptures converge in their methods of coping with scientific or medical innovations. Scriptural texts may be discovered to condemn the innovation; or to sanction it where it does not appear too threatening. In the former case, innovators may enlist the help of modernizing religious scholars, to declare that the texts invoked in condemnation cannot apply to the innovation, since in their original context and language the words could not have the modern meaning. With such hermeneutic manipulation, the march of scientific progress is seldom long impeded, even if the route sometimes turns out to be circular.

In Conclusion

This paper is not intentionally *for* or *against* any item in the matrix, though terms such as "vegetablization", "infanticide" and "ability apartheid" are admittedly not neutral. However, to show the items as a continuum is to suggest that grey areas do exist, which will be unacceptable to some PERILS. To adopt a mostly descriptive position inevitably threatens those who feel their own position relativized and annoys those who prefer to construct their world in clear-cut, adversarial terms.

An influential part of the process of change will be the development of terminology more appropriate to constructive debate and more tolerant of ambiguities. New terms are most likely to be needed at the apparent boundaries between compartments of the matrix, where lines may need to be redrawn or areas of overlap be incorporated. The matrix shown here is an entry-point for more sophisticated designs which will give framework to specialized debates.

An influential part of the process of change will be the development of terminology more appropriate to constructive debate and more tolerant of ambiguities.

Influenced by increasing medical knowledge and technology, the major PERILS have been shifting during the past 30 years from positions traditionally held. More changes seem inevitable. Consideration of bioethical issues as the continuum shown in the present matrix or in expanded versions, may help to clarify thoughts, beliefs and reasoning among those people who are prepared to grapple with complexity. It should also facilitate the education, and thereby the participation, of non-specialists who need a conceptual framework with which to approach the field. Increased input may be

It can hardly be proven in advance that every major culture has a needful contribution to bioethical debate, but the insights gained by inter-cultural exchange in other human fields such as art, literature, music etc. indicate that it is highly probable.

expected from sociologists, seeking links between different social systems and the broad spectrum of bioethical decision-making discussed here.

Equally important will be the entry of non-Western currents of thought into international bioethical debate, challenging the cultural hegemony of Europe and North America. Useful non-Western input is less likely where debate focusses on the ethical fine-tuning required by the latest technological advance. The more valuable contribution may be in comparing conceptual frameworks and noting where and how they differ. Western professionals should facilitate this contribution, as an act of faith. It can hardly be proven in advance that every major culture has a needful contribution to bioethical debate, but the insights gained by inter-cultural exchange in other human fields such as art, literature, music etc. indicate that it is highly probable.

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Nazi Scientists and Ethics of Today

by Isabel Wilkerson, Special to The New York Times, Minneapolis, May 19 (1989)

"You can't think about contemporary issues of medical ethics outside the shadow of the Holocaust."

Nearly 50 years after Nazi scientists performed brutal experiments on Jews and gypsies in the concentration camps, scientists are still struggling with ethical questions over use of the Nazis' data.

But the debate has taken on a more urgent tone as scientists are faced with the dilemmas posed by the potential abuses of modern medical advances, like the ability to determine the sex or potential deformities in a fetus, artificial insemination and test-tube fertilization.

This urgency was behind a conference at the University of Minnesota this week in which about 200 scholars from the United States, Canada, West Germany, Denmark and Israel, along with several Holocaust victims, dealt with the ethical implications of the Holocaust, admittedly with great difficulty and emotion.

"You can't think about contemporary issues of medical ethics outside the shadow of the Holocaust," said Dr. Arthur Caplan, director of the Center for Biomedical Ethics at the University of Minnesota and the chief organizer of the conference. "This is forcing people to confront the evil wrought by medicine."

Children as a Commodity

Scientists at the conference said genetic experiments now in progress, may someday make it possible for parents to choose the height, eye color, intelligence level and the athletic ability of a child.

"In the future, you would be able to manufacture children, through genetic manipulation at the embryo level," said George Annas, a professor of health law at Boston University. "You would not even have to bear the child. You could order embryos from a catalogue and have a surrogate mother bear it for you. This could lead to children being thought of as a commodity."

Dr. Richard King, a medical geneticist at the University of Minnesota, said, "We have nothing in our background to tell us how to handle the information we're generating."

Behind the discussions was the fear that without ethical guidelines there could be future scientific abuses like those of the Nazi era, and the participants spent much of their time agonizing over how the data from the Nazi experiments should be used.

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Politics and Science

Dr. Jay Katz, a professor of law and medicine at the Yale University School of Law, said: "This is not a just a scientific judgment. It is foremost a political one. However hard we might try, we cannot separate the data from the way they were obtained."

The conference focused on experiments in which the Nazis used hundreds of people to test human reaction to long-term exposure to extremes in cold temperatures, air pressure, toxic gases and other conditions, taking blood and urine samples while they monitored their subjects' deaths.

The results of those studies have been available to scholars since the data were discovered shortly after World War II. But in recent years several scientists who have sought to use the

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Nazi research have attracted controversy and stirred widespread soul-searching about the social responsibility and potential abuses of science.

Scientists Voice Alarm

Last year, after nearly two dozen scientists voiced alarm, the Environmental Protection Agency banned the use of Nazi research in a study on phosgene gas conducted for the agency. About the same time, Dr. Robert Pozos, a physiologist, formerly of the University of Minnesota, whose specialization in the study of subnormal body temperature, or hypothermia, was the subject of extensive Nazi experimentation, ignited controversy when he began asking colleagues if it would be ethical for him to use the data.

Many of the Nazi experiments were aimed at protecting military personnel under various conditions but others were aimed at breeding a superior race.

The scientists expressed concern over benign acceptance of Nazi data in modern-day science and the occasional, matter-of-fact reference in contemporary scientific papers. "Nazi data pops into footnotes and is absorbed without comment into mainstream science," Dr. Caplan said. "That I find disturbing."

While some participants said they wanted the data banned completely, most of the scholars were searching for moral and ethical guidelines concerning the data.

"Should we look at data apart from the atmosphere in which it was produced?" Dr. Pozos asked. "Is it ethical to use data gathered unethically? And if we're face with this situation again, what are we going to do?"

Data Should Be Taboo

For some the answer was clear. "The data should be taboo," said Dr. Benno Muller-Hill, a molecular biologist and director of the Institute for Genetics at the University of Cologne in West Germany. "We should remember those who died. We should not try to squeeze profit out of it."

Some participants said that use of the data amounts to the victims' final indignity and could possible invite a duplication of the Nazi experiments. "It's not data, it's a history of atrocities," said Eva Kor, a Holocaust victim, who was among the 1,500 pairs of twins who were the subjects of experiments by the Nazi physician Josef Mengele.

But others said it served no purpose to science to ignore data that could help people. "We are talking of the use of the data, not participation in these heinous studies, not replication of atrocities," said Dr. Benjamin Freedman, a bioethicist at McGill University in Montreal. "The wrongs perpetrated were monstrous; those wrongs are over a done. How could the provenance of the data serve to prohibit their use?"

Commemorating the Victims

Others said the data could be used to commemorate the victims. "The question is not whether we should use the data, but how," said Dr. Robert Proctor, chair of the Science, Technology and Power program at the New School of Social Research. "It should be used if the circumstances under which it was conducted are acknowledged and could be dedicated to the memory of the victims. It should not just say, 'For more on this topic, see Mengele, 1942.'"

Dr. Velvl Greene, director of the Jakobovits Center for Jewish Medical Ethics at Ben Gurion University in Beer Sheva, Israel, argued that scientists could actually benefit from confronting the wrongs of the Nazi physicians. "The need is to put the Holocaust and the Nazi experiments directly under the floodlight on center stage," Dr. Greene said, "even if some of us and our past and present guilt are partly illuminated under the glare."

While some of the scientists said that the Nazi experiments offered singular insights into human physiology, others questioned the validity of the experiments, saying they were poorly designed, could obviously not be tested or duplicated, were conducted on subjects who were weak and malnourished, and therefore, are useless to modern science.

"I don't think lives hang in the balance," said Dr. Caplan. "I think we can find out what we need to know from other sources. I'm convinced we know what we need to know."

The subject brought pain and agony to many of the scholars, some of whom had lost relatives in the Holocaust; others who said they were at once intrigued and angered by the data. They came up with no conclusions, only more questions and a stronger thirst for answers.

Ethical & Policy Issues in Rehabilitation Medicine

by Arthur L. Caplan, Daniel Callahan and Janet Haas

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The field of medical rehabilitation is relatively new, a product in great part of the rapid developments of medical science during and after the Second World War. Until recently, the ethical problems of this new field were neglected. There seemed to be more pressing concerns as rehabilitation medicine struggled to establish itself, sometimes in the face of considerable skepticism or hostility. There also seemed no pressing moral questions of the kind and intensity to be encountered, say, in high-technology acute care medicine or genetic engineering. With eyes focused on the dramatic and wrenching problems, those in biomedical ethics could and did easily overlook the quiet, less obtrusive issues of rehabilitation.

With the support of a grant from the Mabel Pew Myrin Trust, The Hastings Center set out in 1985 to rectify that situation. Various friends and colleagues in rehabilitation medicine had for some time been pointing out to us the wide array of moral issues confronting the field. They ranged from some familiar issues at the clinical level—informed consent, truth-telling, paternalism—to some no less familiar at the societal level, such as the allocation of scarce resources. Yet if these issues were, in one way, familiar, their context was different from acute care medicine, often strikingly so. Rehabilitation therapy is a long process, often allowing much time for the moral struggles to unfold and play themselves out. There is a great need for active patient participation in his or her own treatment as well. Use of treatment teams and the frequent need for family involvement add their own special ingredients to the medical and ethical mix.

To explore the issues, the Center assembled a group of practitioners in the field, Hastings Center staff members, and individuals experienced in other areas of medical ethics. For project participants, there was a difficult and extended period of exploration and analysis; the issues were surely there, but they were not always easy to define with precision or to pursue with vigor. Unlike other areas of medical ethics, there was little pre-existing literature, no specialists in the moral problems, and no tradition or history of interdisciplinary work between rehabilitation and ethics. It was, in many ways, one of the hardest projects ever *mounted by the Center, not simply because the moral problems encountered were complex, which they were, but because they often seemed elusive. We ended the project with a sense that we had made some progress, but humbled that we had made less progress than we would have liked. There is still much work to be done.*

The report that follows was written by Arthur Caplan and Daniel Callahan, assisted by Dr. Janet Haas of the Moss Rehabilitation Hospital in Philadelphia. It owes much, however, to the project participants, who gave gladly of their time, research, and insights. A separate collection of papers and case studies developed by them is being prepared for publication. We acknowledge with gratitude their help. We no less want to acknowledge the support of the Mabel Pew Myrin Trust.

—Daniel Callahan
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As part of the overall project on ethics and rehabilitation, a series of case studies, with accompanying commentaries, was developed. These are available in a photoduplicated form at a nominal price and are suitable for teaching and other instructional purposes. Write to: Publications Department, The Hastings Center, 255 Elm Road, Briarcliff Manor, NY 10510 for further information.

Until recently the ethical issues in the field of medical rehabilitation had received relatively little explicit attention. Most clinical practitioners or scholars in philosophy, theology, law and the social sciences focused their analyses of moral problems in health care almost exclusively on emergency or acute medical interventions.

In part, such neglect may be a result of the fact that rehabilitation is a relatively new specialty within the realm of health care. Rehabilitation only began as a distinct field during World War II when such pioneers as Howard A. Rusk and Henry Kessler, building on the work of Frank Krusen, demonstrated the efficacy of rehabilitation to return soldiers to active duty rather than mere convalescence. The medical specialty was created in 1947 with the formation of the American Board of Physical Medicine under the guidance of Frank Krusen. To date, fewer than three thousand physicians are certified as specialists in rehabilitation medicine.

However, the newness of the field is not an entirely satisfactory explanation for such analytical neglect. Other recently developed areas of health care such as neonatology have produced a great deal of ethical discussion. Obviously, there must be other factors that have caused ethicists and practitioners to overlook rehabilitation medicine.

Rehabilitative therapy depends upon the efforts of many different health care specialists, both physicians and non-physicians. Their efforts frequently extend over long periods of time. Moreover, rehabilitation rarely results in dramatic "cures." Normally, it does not make extensive use of life-saving technologies. Without the use of these dramatic interventions, the moral questions become more amorphous, less obviously responsive to established ethical paradigms.

Those most often in need of rehabilitative services are those already undervalued by the society. Many are elderly. Some have congenital disabilities. A large proportion are unable to work. In a society that places great value on youth, vigor, and industriousness, and manifests an ongoing trust in the power of science and medicine to reverse the effects of disease and disability, there are powerful stigmas and little prestige associated with patients who lack both highly valued characteristics and the capacity for cure.

In spite of these obstacles, in the past few years there has been a significant increase of interest within and outside the field of rehabilitation medicine in ethical issues. In part, this reflects changes in social attitudes toward disability. Some of the stigma associated with physical and mental impairment has begun to wane as a result of concerted efforts by consumer advocacy groups, rehabilitation professionals and self-help organizations such as the Independent Living Movement.

In part, the sudden spurt of interest in rehabilitation ethics is a response to increasing pressures to contain costs. Discussions about the desirability of introducing some form of prospective payment or capitation-based financing into rehabilitation have encouraged professionals in the field to examine seriously their moral obligations both to their patients and to society.

And, in part, because persons with severe neurological injuries can survive for increasingly longer periods of time, rehabilitation professionals must begin to address the moral dilemmas raised by treating patients whose capacity for independent living or autonomous behavior may be moderately or severely impaired. While small in overall numbers, the class of patients receiving rehabilitation who are brain injured are highly visible to providers, administrators and third party payers in terms of both costs and the level of resources they utilize.

It is clear, then, that medical rehabilitation differs in many important respects from emergency or acute medical care. It is also clear that interest in the unique ethical issues of rehabilitation is on the rise. It is, therefore, essential both for bioethicists and for those who deliver or receive rehabilitative services to identify the salient moral dilemmas and to determine whether ethical analysis based on emergency or acute care paradigms is adequate.

Rehabilitation Today

What Sorts of Services Are Provided and By Whom?

It has been said that rehabilitation is a medical specialty lacking an age, organ, technology or appendage to define it. Those providing rehabilitative therapy must treat the whole person rather than discrete physical, emotional or sensory dysfunctions. They also wish to provide treatment that addresses the individual needs of particular patients. In the words of Howard Rusk, the goals of rehabilitation are to restore persons "to optimal self-sufficiency and functional performance." To accomplish these goals involves the provision of a broad range of services including medical and nursing care, psychological counseling, family and social services, vocational assessment and management, sexual counseling, reconstructive surgical interventions, electrodiagnosis, massage, exercise, training to carry out activities necessary for daily living such as cooking and grooming, and the provision of prosthetic and orthotic devices.

Services are provided by a diverse group of professionals. A single patient might be treated by a variety of specialists including a physiatrist (a physician specializing in rehabilitation), medical consultants, one or more physical therapists, a speech pathologist, an occupational therapist, a psychologist, a psychiatrist, a social worker, a vocational counselor, a recreation therapist, a large number of nurses with various degrees of specialty training, and, if the person is treated in a teaching facility, a host of students. The term "team approach" has been coined to indicate the variety of specialists involved in the provision of coordinated rehabilitative services.

A team model requires various specialists to provide different types of care in order to restore or compensate for loss of function. A physiatrist coordinates the activities of all medical specialists and works with the team to formulate and monitor each patient's plan of care. In some facilities a case manager, often a social worker, also is responsible for monitoring care and formulating a post-hospital or continued care plan. This carefully coordinated multidisciplinary approach to the provision of care, involving the sharing of responsibility and authority among a broad spectrum of health care professionals, has few analogues in other areas of health care.

Who Are the Patients?

Approximately one third of those who receive rehabilitative care have some form of neurological impairment most often caused by automobile accidents, falls, swimming mishaps, industrial accidents or gunshot wounds, injuries to the spinal cord, and strokes. The percentage of those with strokes has been declining in recent years. The number of patients requiring rehabilitation for neurological dysfunction as a result of injuries to the head, spinal cord, or both, is growing at a rapid rate. Other major causes of neurological impairment include multiple sclerosis, Parkinson's disease, cerebral palsy and muscular dystrophy.

Another third of patients who receive rehabilitative treatment have musculoskeletal impairments including arthritis, traumatic skeletal injuries, and amputation. The remainder have varied impairments associated with cancer, chronic heart and lung diseases, and diabetes.

With the introduction of antibiotics and life-support technologies, larger numbers of rehabilitation patients are elderly, having survived illnesses that would have once proven fatal. In addition, a growing proportion of those requiring rehabilitative assistance are children, many of whom have survived life-threatening diseases or congenital anomalies because of improvements in neonatal and pediatric intensive care.

How Is Rehabilitative Care Paid For?

The financing schemes that have evolved for those requiring medical rehabilitative services present a complex and confusing bureaucratic array. As a rule, reimbursement by third parties tends to cover only acute, short term hospital stays, thereby creating many gaps in the coverage presently available for reimbursing the costs of rehabilitative services.

Some private medical insurance policies cover only those costs incurred in acute care hospital settings. A small number of insurance firms have begun to write policies to provide for out-patient services and long-term care but even these policies usually have time limits for benefits that are far less than the amount of time necessary for adequate rehabilitation to be completed. Some private accident insurance policies and some group health plans also cover rehabilitation, but again often with strict limits on the amount, setting and duration of care that is compensable. Many prepaid medical plans do not cover rehabilitation services.

Most older Americans and those who are disabled, defined as those who have received Social Security Disability benefits for two years, find the primary source of payment for their medical care in the Medicare program. Medicare has two parts: Part A (Hospital insurance) and Part B (Medical insurance). Each part has a yearly deductible; in 1987 it is $520 in Part A and $75 in Part B.

Part A covers medically necessary care in a hospital. Sixty days of care are covered in full, the next thirty days are partially covered with a co-payment requirement of $65 per day. Those eligible for Medicare may also draw upon a one time allotment of an additional 60 days of care with a co-payment, in 1987, of $260 per day.

Part A of Medicare covers the costs of rehabilitation provided in a hospital setting, including therapies and drugs, within the coverage periods of the program. The costs of medical equipment can be reimbursed if the equipment is ordered and delivered to the patient in the hospital during the time period of coverage.

Part B of Medicare is optional; potential beneficiaries or their employers may enroll for a monthly fee of approximately eighteen dollars. Part B covers outpatient care at a rate between 68% to 80% of costs. Patients are responsible for paying the balance. Part B will cover doctors fees as well as those services provided by skilled professionals such as nurses, physical therapists or speech therapists both in the hospital and the home.

The major source of funding for the poor is Medicaid. Eligibility for this program is determined by a means test. The income requirements and extent of coverage are determined by individual states that administer this program.

Those seeking eligibility under the program are required to be poor or become poor by spending down their resources to reach the indigency level defined by the state in which they reside. Many elderly persons must expend all of their resources in order to obtain coverage beyond that allowed in Medicare from Medicaid.

Medicaid coverage varies enormously from state to state. In some states Medicaid will pay for an unlimited number of days in a hospital or nursing home. In others, limits may be as low as fourteen days of coverage.

In many states Medicaid will not pay the costs of wheelchairs and other forms of equipment. In others the program will pay for some home care and some forms of equipment.

Public insurance for in- and out-patient rehabilitation, medical equipment, home care and nursing home care exists in limited form and varies enormously from state to state. Eligibility for publicly funded insurance often requires patients to impoverish themselves.

Concerns about the cost of health care, both acute and long term, have led many within the field of health care to reexamine the level of support that ought to be made available for those seeking rehabilitative services. In attempting to decide the level of support that society ought to provide, it is necessary to understand the nature of the aims and goals that providers and patients bring to this phase of care. In large measure, social consensus as to the desirability and feasibility of attaining the goals set by those who provide rehabilitation determines the availability of public reimbursement for this type of care.

Goals In Rehabilitation Medicine

Rehabilitation differs from other areas of health care with respect to the models of care that guide the efforts of health care professionals in dealing with patients. While scholars within and outside the health care professions have made numerous efforts to expand the standard view of health care in acute care settings, what is often referred to as the "medical model" remains influential in many areas of medicine.

The medical model of disease focuses upon the medical response to the sudden and unexpected onset of serious and often life-threatening disease or injury. The disease or injury is almost always the result of infection, accident or unanticipated physiological failure.

Illness—the perception on the part of the patient that something is wrong or abnormal—is understood to be the outcome or product of disease. While it is possible on the medical model for there to be disease present without the symptoms of illness, as in the early stages of breast cancer or hypertension, the converse situation, illness without disease or injury, is viewed with much skepticism.

The goals of care that dominate rehabilitation medicine, while sometimes overlapping those expressed in the medical model, are frequently far broader in scope.

The reductionist view of disease implicit in the traditional medical model has prompted some to argue that values or ethics play no role whatsoever in the definition of disease. While values may play a role in understanding illness, disease can be defined as either any deviation from statistically normal parameters of organic functioning or, as any deviation from species-typical functioning.

On the traditional medical model, there is no need to ascertain the patient's values or, for that matter, anyone else's values in the course of making a diagnosis. One simply detects abnormalities of physical functioning that are, on occasion, not even detectable by the patient, and then undertakes a series of interventions calculated to reverse or obviate organic dysfunction. On the medical model, disease is seen as a process that affects individual persons who then become the locus of medical attention and intervention.

The physician plays a critical role in this model of care in terms of both expertise and accountability. The patient expects the physician to use the knowledge and skill available in the various specialties of medical science to reverse the course of pathological processes in the body or the mind. Anything less than 'cure' is viewed in a negative light by both health care providers and patients.

The goals of care that dominate rehabilitation medicine, while sometimes overlapping those expressed in the medical model, are frequently far broader in scope. In medical rehabilitation professionals are more likely to assume that they are dealing with dysfunctions that are chronic, irreversible at the physiological level, relatively stable but, nevertheless, disabling. The subjective experience of illness helps guide the course of rehabilitative care. Patients play a crucial role in informing the health care team as to the extent to which any impairments that are present produce dysfunction or disability.

While rehabilitative interventions focus on the patient, providers also try to contend with the interaction of pathology and environment since extrinsic factors may exacerbate disability or produce additional handicaps.

Health care professionals in rehabilitation often see themselves as teachers or educators. They view themselves as responsible for teaching patients adaptive strategies and techniques for carrying out the activities of daily life and for maintaining health.

The traditional medical model tends to depict patients as the passive recipients of medical interventions. On the rehabilitative model, patients are commonly viewed as active agents who must participate in their own care, e.g., learning particular exercises intended to strengthen muscles damaged by injury or disease.

The goals of health care in the medical model are to remove or reverse physiological pathology in order to restore normal or typical functioning in organs or organ systems. Medical rehabilitation includes these goals when possible but also seeks to reestablish emotional well being, preserve residual function, prevent disabling complications and to develop compensatory functional capacities needed for carrying out daily activities.

Acute care and rehabilitation may be seen as two endpoints across a spectrum or range of goals within health care. In acute care more emphasis is given to cure. In rehabilitation the goal of interventions is "care-driven"—health professionals try to teach patients and their families how best to accommodate to and make the most of the consequences of chronic impairment.

Values play an important role in diagnosis or treatment in rehabilitation. Impairments in speech, vision, learning ability or memory have different meanings for patients who are children, adults who are the sole sources of financial support for others, or those who are in their post-retirement years. The degree to which a particular patient can tolerate pain, cooperate with a treatment plan, or feels handicapped in carrying out certain activities powerfully influences the course of care for each patient. The values of health care professionals and their patients, while not always explicitly acknowledged, are inextricably present at every step in the formulation of treatment plans.

Phrases such as quality of life, ability to work, ability to live on one's own, ability to resume an active life, and independent living, which only occasionally manifest themselves in the emergency room or intensive care unit, are present at all times in the construction of a diagnosis and the subsequent formulation of a treatment plan in rehabilitation settings. Quality of life considerations play a key role in guiding the course of rehabilitation.

The fact that medical care in rehabilitation is unavoidably value-laden creates a variety of ethical questions of a kind that rarely arise when health care providers and patients agree about the goal of care. Since patients and providers bring different values to the rehabilitation setting and evaluate outcomes differently according to their individual norms, disagreements may arise concerning goals or the priority that ought to be assigned to achieving particular goals.

Disagreement can take many forms; between providers and patient, between patient and family, or among the various members of the rehabilitation team itself. Third-party payers and government officials may also advance values for the provision of rehabilitation, perhaps values that elicit little enthusiasm among providers or patients, i.e., ability to work. Of course patients, families and providers do not always disagree about the goals that ought to guide the formulation of treatment plans. But the absence of a single overriding goal—cure—means that the values of providers, patients and families are more likely to collide in the rehabilitation setting.

An especially important ethical challenge confronting health care providers in rehabilitation settings is to obtain agreement from those in their care as to what abilities and capacities constitute an acceptable quality of life. Patients who place high value on work, on hobbies, on communication, may have goals that are unrealistic or impossible to obtain to a degree consistent with their level of physiological impairment. Providers therefore must not only restore function to the extent possible, but also convince patients to reevaluate functional abilities or capacities in light of irreversible impairment, e.g., using a wheelchair for mobility rather than walking. The process of achieving accommodation between patients, their families and friends, and providers as to what constitutes an acceptable quality of life is one of the most arduous tasks faced by those involved in rehabilitation medicine.

While it is often said that the concept of "quality of life" is too ambiguous to admit of consensus, rehabilitation professionals have little difficulty in identifying central components of this concept. Rehabilitation programs, at least in the initial stages of treatment, stress the importance of the acquisition of skills that will permit independent living, work, and mobility. However, the emphasis placed on these particular goals is very much a function of the social and economic realities that face those with chronic impairments and disabilities.

In a society that values autonomy and independence and that frowns upon dependence on either charity or assistance from others, great stress must be given to the restoration of physical and social skills that will maximize the prospect for independent living. In a society that emphasizes the importance of work and employment in establishing both personal identity and dignity, efforts must be made to teach adaptive skills that will contribute to the possibility that those of non-retirement age will be able to find some sort of remunerative employment.

Obviously, the values expressed in the ways in which the quality of life is understood in rehabilitation are highly sensitive to existing social mores and attitudes. One of the major, if relatively unexamined, ethical challenges facing those in rehabilitation is the degree to which they must orient their treatment regimens to reflect the realities that confront those who have various degrees of functional impairment.

Should rehabilitation specialists try to restore mobility to persons who ultimately must return to a world not readily accessible to those who rely upon canes or wheelchairs? Should rehabilitation specialists stress the value of work in designing treatment plans for patients for whom employment may not be of great personal value? And ought rehabilitation specialists advocate the availability of more assistance to those who are homebound rather than to teach people to live as independently as they can without the assistance of others?

Because many of the disabilities requiring medical rehabilitation are preventable, professionals also may have an obligation to take an advocacy role concerning the prevention of impairment, e.g., helmet laws, the use of air bags in automobiles, the installation of special lanes for bicycles on city streets. While acute health care professionals are appropriately concerned with prevention, the obligation for rehabilitation professionals appears to be especially compelling.

The Selection of Patients

Decisions to Admit Patients to Rehabilitation

One of the most distinctive aspects of rehabilitation in the United States is that practitioners choose their patients. Disabled Americans are not, in general, entitled to reimbursement for rehabilitative care. Nevertheless, historically, the supply of such care has fallen short of the demand for it. Clinical practitioners faced with the reality of a demand that exceeds supply have had to review potential patients in order to select those who would receive treatment.

Generally speaking, decisions as to whether rehabilitation will be initiated involve a two stage process. Most of those who receive rehabilitative care are referred by physicians practicing in acute care settings. Once a referral is made, a decision must then be made as to whether a patient is an appropriate candidate for rehabilitation.

Some physicians do not consider rehabilitation as an option with the result that physiatrists are not always given the opportunity to consider the possibility of transferring a patient to a rehabilitative setting. The selection is difficult to challenge either by the patient or members of the rehabilitation team since no formal mechanisms exist for review of decisions at this stage of the rehabilitation process.

Once a referral has been made, it is usually a physiatrist who screens potential candidates for rehabilitation. The information used to make initiation of treatment decisions is derived from patient records, consultation with other physicians who have already treated the patient in acute or emergency settings, and usually, but not necessarily, direct physical examination of the candidate. Unfortunately, communication between physicians in acute and rehabilitation settings is not always as comprehensive as it ought to be.

When referrals are made, physiatrists consider a variety of medical and nonmedical factors in determining whether or not to initiate rehabilitation. In the area of nonmedical factors, potential candidates will have their financial and insurance status reviewed by administrative personnel. Social workers may review a potential candidate's family or social situation. The primary reason for such an assessment is to insure that the disposition of the patient will not be a problem once rehabilitation has been completed.

Among medical factors, diagnosis and prognosis are paramount considerations. Some physicians believe that persons with particular types of impairments, such as those resulting from stroke or spinal cord injuries, are likely to demonstrate functional gains from rehabilitation. Other diseases such as Alzheimer's or terminal stages of cancer are viewed by some as being less amenable to successful intervention and therefore of lower priority in access to treatment.

Relatively minor impairments in cognitive or sensory capacities may be given great weight since these deficits may significantly impair the patient's ability to participate in a rehabilitation program. Or the physician may believe that the degree of effort and amount of resources necessary to help patients cope with cognitive or sensory dysfunction may be so large as to diminish the availability of resources for other patients.

It is clear that the field of rehabilitation must make a concerted effort to subject its practices and techniques to carefully controlled clinical trials.

Other factors that bear on decisions to initiate care are: the amount of progress that a patient is likely to be able to make, the age of the patient, and the ability to learn. Patients who are seen as capable of achieving great improvement, even if they begin with high degrees of dysfunction, are likely to be given preference in access over other patients for whom the level of improvement that is possible may be less even if they initially start with higher degrees of function.

Age is viewed as relevant for two reasons. First, younger patients are believed to have greater capacities for regaining lost function simply as a result of greater physiological malleability. Second, younger patients may receive priority over older patients in receiving access to rehabilitative care on the grounds that the net benefits are likely to be greater in terms of length and quality of life. This is so for the simple reason that younger candidates will, in all likelihood, live longer than older candidates.

Some third-party payers require that patients seeking admission to rehabilitation programs demonstrate "vocational potential." They believe that such an ability must be present since part of the overall goal of treatment in some facilities is the restoration of the ability to work.

The ability to pay is a powerful determinant of access to services. Institutions often convey information to admitting physicians as to the financial needs of the hospital. Unless a facility receives public funds, financial clearance is a necessary first step for admission at many facilities.

Some facilities do designate a few beds as "Medicaid beds." Once these are filled, no other Medicaid dependent patients are admitted. Institutions may also wish physicians to give preference in admissions to those with more comprehensive forms of insurance or those for whom discharge is unlikely to be a problem. Institutions providing rehabilitation services are accorded a wide degree of authority concerning admissions by government and regulatory agencies.

The dominant factors that seem to guide physicians in the admissions process are efficiency, potential for benefit, potential for success, the anticipated burden that will be placed on staff members in the provision of care, and the ability to pay. The way in which these factors are applied varies greatly from physician to physician and facility to facility.

The degree of freedom accorded providers to make judgments regarding access to rehabilitation carries with it the danger that subjectivity or bias may enter into the decision. Physicians have enormous discretion in making admissions decisions since there is no formal, or public set of criteria governing the decisions that are made. Few checks and balances exist to modulate the effects of personal or professional bias.

Patients may not be told about the reasons for their rejection by particular facilities. Sometimes when reasons are given they are not always accurate or complete.

It is clear that the field of rehabilitation must make a concerted effort to subject its practices and techniques to carefully controlled clinical trials. Those involved in making admissions decisions must be encouraged to provide written documentation of their decisions and the reasons for them. Periodically, such information ought to be made available to other members of the rehabilitation team for assessment and discussion. Greater efforts must be made to study the admissions process and to communicate the factors involved to the public. This information would help explain why candidates are or are not accepted at particular facilities. It might also provide a necessary system of checks and balances to assure those in need of care that they have an equitable opportunity to receive it.

Decisions to Initiate a Specific Course of Care

Those admitted for a course of care in medical rehabilitation settings are frequently advised that they must take an active role in determining the goals of their treatment. Candidates are usually eager to participate in the formulation of a treatment plan that meets their own desires and values. This is especially so since most patients come from acute care settings where they have occupied an essentially passive role vis-à-vis their own treatment.

Team members approach the initial determination of goals with different assumptions from patients and their families. Professionals are keenly aware of the central importance of patients adjusting to the realities imposed by impairment. However, to some extent the nature of these realities are products of economic, social, and physical constraints that able-bodied society imposes upon those who have impairments.

The desirability of involving patients in taking responsibility for their own treatment is necessarily tempered by the recognition that society is not always willing to provide the social, architectural, recreational, and vocational resources that would allow those with impairments to take full advantage of their abilities and capacities. To date, in some facilities, the practice of rehabilitation is characterized by a willingness to accept the constraints imposed by society and to initiate courses of treatment that reflect these boundaries. But it is not clear that patients ought be persuaded to accept such limits or to what extent persuasion lapses over into coercion in attempting to formulate a treatment plan to which provider and patient can both agree.

In some facilities patients are encouraged and taught to be advocates for their interests, to agitate for changes in social and public policy through community involvement. But in other institutions little concern is manifest for coping with or modifying the social and economic barriers that those with disabilities often face upon discharge from a rehabilitation setting.

Ethical Issues In Provider/Patient Relationships

The nature of the moral rules and principles that ought to govern relationships between health care providers and their patients is one that has received a great deal of attention in the literature of bioethics. Most of the discussion of provider/patient relationships presumes a situation in which a physician is the sole provider of care. It is also presumed that each patient must reach some accommodation with his or her physician as to the type and intensity of care that will be given.

In the interaction between doctor and patient, ethical questions arise regarding what moral rules ought to govern the exchange of information and, ultimately, the provision of services by the physician to the patient. Central to the moral dimensions of this relationship are such topics as truth-telling, informed consent, privacy, confidentiality, and the responsibility to continue care once a relationship has been initiated.

The Traditional Model: Medical Paternalism

Historically, discussions of the ethics of provider/patient relationships presumed a relationship between a treating physician and a patient seeking care. The medical profession articulated a number of codes of conduct intended to provide guidance as to physician responsibilities in providing care. The moral requirements reflected in documents as diverse as the Hippocratic Oath and the American Medical Association's *Principles of Medical Ethics* enjoined physicians to act only so as to "benefit" patients and to "do no harm" or "keep patients from harm." Physicians were held to be bound by the principles of beneficence, the duty to help those in need, and nonmaleficence, the duty not to harm those seeking care. These principles were seen as sufficient for constituting the framework within which physicians and patients ought to interact.

On this model, which dominated the practice of medicine well into the twentieth century, physicians made decisions about what care was in the patient's best interest. Patients had the right to end a medical relationship, but physicians were obligated to provide patients only with information that, in their medical judgment, they needed to know.

Medical paternalism casts the physician in the role of the zealous advocate of the patient's best interests. It is the physician who is in the best position, as a consequence of specialized knowledge, skills and clinical experience, to determine which medical interventions are most appropriate.

The Contractual Model

A number of critics of medical paternalism, both within and outside of medicine, have argued for a more egalitarian model of physician/patient relationships. They believe that physician/patient relationships ought to be seen as based upon a contract between parties who are on an equal footing.

On the contractual model of doctor/patient relationships, physicians are morally responsible for providing care, but only such care as is desired or requested by patients. The desire to be beneficent in the provision of medical care is, on the contractual model of physician/patient relationships, limited by respect for the autonomy of individual patients. Patients may, if they choose, reject care that is known to be beneficial as long as such refusals are based upon voluntary informed choice.

The doctrine that has emerged as the guarantee of individual patient autonomy on the contractual model is informed consent. Patients have an absolute right to make informed choices about the kind and degree of care they wish to receive. While physicians are under no obligation to comply with the wishes of patients when they are at variance with their reasonable medical judgment, they cannot undertake any interventions without the express permission of the patient.

American courts have, in the past thirty years, shown a willingness to codify the right of patients to retain authority over their medical care. A number of state courts have explicitly acknowledged that patients have a right to be informed of the risks and benefits associated with various courses of medical care. In most court cases, the standard of informed consent has been interpreted as what a reasonable patient would want to know.

As the contractual model has come to have greater significance in medicine, there has been a steady shift in clinical practice toward the recognition of a presumptive duty to share information about diagnoses and prognoses with patients. If it is true that patients ought to have the right to control their medical care, if respect for autonomy carries more moral weight than the obligation of beneficence when these moral principles come into conflict, then patients have a right to know and physicians a duty to tell the truth.

If a patient is mentally competent, as reflected in an ability to understand and deliberate about information concerning the risks, benefits and consequences of medical treatment or the failure to initiate treatment, then patients have the right to make choices about each and every aspect of their medical care. Differences of opinion between patient and physician are not in and of themselves sufficient grounds for challenging patient competency.

The contractual model of physician/patient interrelationships assigns a high value to confidentiality and privacy. It is the patient who can and should decide who will have access, if anyone may, to information about his or her diagnosis and medical care.

Does the Contractual Model Apply in Rehabilitation?

Informed consent is a much more problematic concept in the context of rehabilitation. While health care providers in the field of rehabilitation recognize the importance of informed consent in principle, in practice they are not always thorough in their efforts to obtain consent.

For example, in some cases a patient may sign a consent form for surgery or the provision of medications as a part of the development of a treatment plan in rehabilitation, but never be asked to provide consent for such interventions as physical therapy, occupational therapy, or vocational counseling. Consent may be obtained early on in the course of rehabilitative care for a particular treatment regimen, but, although such care may extend over months or years, no further attempts may be made to reaffirm patient consent.

The contractual model of informed consent takes the one-on-one relationship between a physician and a patient as paradigmatic of medical practice. But in rehabilitation patients rarely receive care from a single physician. Candidates must deal with a host of health care providers of differing backgrounds, types of expertise and personal values. It is not surprising that the contractual model and its linchpin, the doctrine of informed consent, encounter practical difficulties given such a complex set of provider/patient relationships.

It has been noted already that patients and their families must assume active roles in the provision of care if the efforts of rehabilitation specialists are to be maximally efficacious. Provider/patient relationships must, as a result, reflect the involvement of third parties—spouses, children, parents, friends, etc.—whose role is simply not acknowledged in the contractual view of provider/patient relationships. Issues of privacy and confidentiality are made far more complex by the practical realities associated with the involvement of many parties, both medical and nonmedical, in the provision of care.

Moreover, many professionals in rehabilitation would readily acknowledge the priority that ought to be accorded the principle of respect for patient autonomy. But their clinical experience with patients who have suffered severely disabling injuries or diseases makes them skeptical about the ability patients possess to make informed, deliberative and reasoned choices concerning the risks and benefits of treatment.

The competency of patients in the earliest stages of rehabilitative care is called into question on three grounds. First, many rehabilitation professionals do not believe that patients can fully appreciate the risks and benefits of rehabilitative care. They will note that it may take weeks or even months for a patient to begin to understand the ways in which rehabilitation may make it possible to cope with severe disability.

Second, even when there is no doubt that patients who are entering a rehabilitation program are mentally and emotionally competent, experienced clinicians may still be reluctant to honor patient initiated refusals of care. It is not clear that a person who has lost the use of his or her limbs, cannot speak or be understood, or who has been disfigured by a burn or other injury can immediately adjust to the challenge to self-identity implicit in irreversibly disabling injury or disease.

Third, surrogate decision makers such as a spouse or parent have a similar problem adjusting to the patient's new identity and future limitations. From experience rehabilitation specialists have noted that even family members cannot project what the patient's wishes will be in the months and years ahead. The fact that most patients who initially refuse care change their minds and begin to participate actively in rehabilitation therapy makes many rehabilitation specialists reluctant to honor the choices and requests that patients or their families make at the beginning of a course of rehabilitation. Time must be given for those who suddenly find themselves impaired or disabled to absorb the reality of disability into their sense of personal identity.

The contractual model presumes that the patient is both competent to make rational decisions and willing to do so. Rehabilitation professionals are often faced with the challenge of trying to restore or encourage autonomous behavior in patients who are depresssed or demoralized by the severity of their impairments. The trauma of sudden, severe, and incurable disability leaves some patients emotionally unwilling to try and make decisions for themselves even though they retain the cognitive capacities to do so.

The capacity for free, voluntary choices may have to be facilitated in patients since it may be unrealistic to expect such capacities to be present in those who have suffered grievous and irreversible impairments. The challenge facing medical professionals in rehabilitation is frequently not how to respect autonomy, or whether to obtain informed consent at every stage in the rehabilitative process but, rather, what steps and activities, and with what degree of persuasion or even coercion, are morally permissible in the hope of restoring autonomy.

Moreover a greater latitude in physician paternalism seems justified when physicians and other health care providers know from previous clinical experience that a process of accommodation and acceptance is necessary in order to allow patients to come to grips with the reality of irreversible impairments. The fact that time is essential in allowing patients to accommodate to the reality of impairment is further confirmed by the fact that some patients report the need to undergo just such a cooling off or accommodation process in learning to accept chronic impairments resulting from disease or injuries.

The Educational Model

Thus the contractual model is difficult to implement for all patients in all phases of rehabilitation. The contractual model is strongly linked to the provision of a highly specific course of care at a specific time by a physician. The concreteness and time-frame presumed within the model are rarely present within rehabilitation.

Provider/patient interactions in rehabilitation require a model of care that is sensitive to the evolving capacities and adaptations that take place between providers and patients over long periods of time.

An "educational model" might be more appropriate to the rehabilitation setting. On such a model, health care providers are allowed more leeway in the initial phases of care to act in a parental manner toward certain patients. They have the right to initially ignore or override patient or family choices concerning the course of care for those who are suddenly or unexpectedly severely impaired in the interest of restoring or maximizing the long-term autonomy of rehabilitation candidates.

If autonomy consists of the ability to make informed, voluntary choices about the course and direction of one's own life then it is necessary for persons to understand fully the options and opportunities that are available to them. When the onset of impairment is sudden and unexpected, it may take time for persons and their families and friends to comprehend and adapt to the reality of their condition. While such persons may be competent to make decisions, they may not fully understand or be prepared to listen to the information that health care providers or those with impairments wish to convey. In this sense, it may be necessary to allow for an infringement of autonomy in the short run in order to insure that subsequent choices are truly reflective of informed, voluntary deliberation.

This means that for some patients the initial stages of rehabilitation are sometimes characterized by paternalistic interventions that would be viewed as ethically unacceptable in the light of prevailing analyses of the ethics of provider/patient relationships. At the same time, this model requires that mechanisms be created for monitoring the capacities and abilities of patients to make autonomous choices and that provisions be created for restoring autonomous control to patients once they have had the opportunity to accommodate themselves to the realities of chronic impairment and disability.

One such mechanism might consist of regularly scheduled meetings between patients, families and team members in order to assure constant feedback between professional points of view and patient perspectives. Another might be the creation of an independent committee to review the course of care for every patient in a rehabilitation setting in order to ensure that confidentiality, privacy, and autonomy are respected to a degree consistent with maximal accommodation to chronic impairment.

An educational model will require health care professionals to state clearly to patients upon acceptance into a rehabilitation program that they will be interacting with a diverse team of health care professionals who share responsibility for the formulation of treatment goals and the monitoring of progress toward meeting these goals. Patients and their families must understand that rehabilitation teams are less hierarchical in their sharing of responsibility and authority than is the case in other areas of health care. At the same time, patients must understand who is responsible at any given time for coordinating the efforts of the team and who holds ultimate responsibility for team management.

Patients should be informed that they have the right to request changes in the composition of the team to the extent that is practically possible in light of constraints on resources and the needs of other patients. They must also recognize that from the start of a rehabilitation program, other persons including family members will have access to information about their diagnosis and prognosis. Agreement should be reached on the degree to which family members will be given a say in the direction of treatment plans and the rationale for such involvement.

Patients also must understand that confidentiality and privacy will be protected but that the realities of a team approach to care require that many persons have access to patient diagnoses and records. The rights of third-party payers to request information concerning the course of care, including psychosocial information, must be explained clearly to both patients and their families.

Patients also should be told that team members must make determinations concerning access to care and the termination of care that are sensitive to the needs of other patients. They should understand as soon as they are capable of doing so that their continuation in a treatment program will depend in part on factors that go beyond the question of whether further benefits can be obtained by the continuation of rehabilitation efforts. They also should be told about the nature of their rights to request continuation of care and the options that are available to them to seek care from other providers in other settings.

The model proposed here is one of an evolving relationship between providers and patients. Its scope is restricted to those patients who have no prior experience with impairment or disability. Its earliest stages are characterized by assigning a higher priority to beneficence than to respect for autonomy. The model requires, however, that efforts to identify and assess levels of competency and autonomy be ongoing and zealous; once it is clear that patients have had an opportunity to accommodate to the realities of their functional impairments, their right to control the direction and composition of their rehabilitative care will be restored to them to the extent consistent with the overall needs of other patients requiring the services of the rehabilitation team.

Implications of An Educational Model: The Termination of Treatment

One of the most controversial issues in all of bioethics is that of when, if ever, treatment ought to be withdrawn from patients. In the context of acute medical care, ethical discussions focus on the authority that patients should have to refuse treatment, the ways in which competency will be determined in deciding whether to honor patient directives that treatment be withdrawn or foregone, the definition of what constitutes a medical treatment and the type of procedural review and oversight necessary for protecting patient interests and welfare where termination of treatment decisions are being considered.

In rehabilitation medicine, decisions to terminate care for a patient are usually made without the pressure of time that constrains those decision-makers in acute or emergency settings. Once a course of rehabilitation therapy has been initiated, there is usually time to discuss and reflect upon questions concerning the termination of treatment.

Termination of care in the rehabilitation context frequently involve decisions about when to transfer a patient from an acute rehabilitation unit or specialized institution to another setting. Once treatment has started, the vast majority of termination of treatment decisions arise when professionals believe that further gains in the restoration of function are not likely within a particular institutional setting or in the context of a particular course of therapy.

The paradigmatic models of termination of treatment decisions in the literature of bioethics are those cases where competent or incompetent patients diagnosed as terminally ill request the withdrawal of various forms of life-supporting technologies such as respirators, antibiotics, cardiopulmonary resuscitation, or the provision of food and fluids. Much of the ethical discussion has focussed on the basis for determining the competency of patients to make such requests. In cases where patients are manifestly incompetent, then moral debate centers on the questions of who should make decisions to withdraw life-supporting technologies and what standards should guide decision-makers faced with such choices.

The single most distinctive feature of termination of treatment decisions in rehabilitation medicine is that they are almost always initiated by health care professionals rather than by patients or their families. Indeed, just as patients are often unaware of decisions concerning their admissibility for a course of rehabilitative care, they are usually not actively involved in the initial decision to consider the matter of terminating care. Increasingly, financial constraints such as limits on insurance coverage or pressures to utilize scarce resources for other patients are the catalysts that compel a rehabilitation professional to consider ending care for a particular patient.

The premiere criterion for guiding decisions concerning the termination of care on the part of rehabilitation professionals is whether a patient has reached a "plateau" in terms of progress toward the goals in his or her treatment plan. Patients in institutional rehabilitation settings are expected to make constant and steady progress toward attaining the goals established by the rehabilitation team. When progress slows significantly—for example, when a patient has regained a significant degree of mobility in a particular joint—members of the health care team may raise questions as to whether further efforts at therapy are worthwhile.

The concept of plateauing is one that seems particularly unique to rehabilitation medicine. Few medical specialties attempt to assess the desirability of continuing medical treatment on the basis of either the rate of progress that patients demonstrate or the degree of progress likely to be obtained if care is continued.

The fact that termination of treatment decisions are usually triggered by professional assessments of progress rather than patient requests means that the moral judgments and values of the members of the rehabilitation team play an extremely important role in the determination of whether plateauing has occurred. Values enter into such determinations in a variety of ways.

If a patient is viewed as non-compliant, poorly motivated, or as having unmanageable behavioral or emotional problems, the rehabilitation team may decide to examine plateauing. Those patients whose financial resources are limited may reach a plateau sooner than other patients who are enjoying similar rates of progress, but have greater financial resources available. The subjective judgments of team members about the ability of a patient to cope with impairments outside the rehabilitation setting strongly influence the kinds of assessments made about the rate of progress of the patient.

One of the major ethical flaws in the current procedures followed by many rehabilitation teams for assessing patient progress is a failure to inform patients and their families in a thorough and clear manner about the criteria used to decide when rehabilitative care should end in a particular setting. More specifically, patients and their families frequently do not fully understand the kinds of progress and the rates of progress that are viewed by professionals as requisite and sufficient for the continuation of care. Nor are patients and their families always aware of financial considerations or that constraints on the availability of resources may and probably will play a role in decisions as to when the rate of progress shown by a patient no longer justifies the continuation of further efforts at rehabilitation.

The single most distinctive feature of termination of treatment decisions in rehabilitation medicine is that they are almost always initiated by health care professionals rather than by patients or their families.

The failure to inform patients fully about the factors that prompt consideration of termination of treatment decisions among members of the rehabilitation team, the lines of responsibility and authority among team members in making evaluations of progress toward treatment goals and the kind of evidence used to assess the desirability of continuing care leaves patients and their families in an especially vulnerable position.

An educational model of professional/patient relationships allows professionals a great deal of discretion early on in the course of treatment of some patients. Such a model permits the initiation of care for brief periods of time for those who initially refuse care, on the grounds that early intervention is critical to the efficacy of rehabilitation interventions, and that many patients need time to accommodate to the possibilities and opportunities associated with permanent impairments of physical or cognitive functioning.

But the educational model requires that health care professionals strive to restore autonomy to patients as rapidly as they can. Rehabilitation professionals must devise procedures whereby authentic autonomous choices can be recognized and heeded after a reasonable period of time has passed to allow patients to accommodate to the reality of incurable impairment. There is no ethical justification on this model, and certainly not in the standard view of professional/patient relationships, for excluding competent patients from any aspect of the decision-making process surrounding the termination of care in rehabilitation.

Indeed, rehabilitation professionals have a strong moral duty to seek actively the involvement of patients and their families in decisions to end care, particularly since such decisions are almost always arrived at through the assessments and concerns of team members rather than patient requests. If rehabilitation professionals are the only persons who can monitor and assess patient progress, then surely patients have a right to know exactly what standard or standards will be used for making such determinations and the sorts of evidence that will be brought to bear in deciding whether the standard has been satisfied.

Efforts to enhance informed participation by patients and their families in termination of treatment decisions must be supplemented by efforts on the part of rehabilitation teams to systematically collect and document information concerning patient progress and plateauing. In many instances, the data that initiates discussions of stopping care rests upon statements or claims made at weekly patient conferences or in casual conversations among team members. Decisions to stop care are too important to leave to informal or casual mechanisms.

Family Duties and Rights

Family members play crucial roles in rehabilitation medicine. In the earliest phases of rehabilitation, the presence of a secure and stable spouse or family is often a critical variable in influencing rehabilitation professionals' decisions concerning the selection of patients for a course of rehabilitation therapy. When decisions are made to terminate care they are often influenced by a patient's willingness or eagerness to return to his or her family and by the family's willingness to undertake care for the patient in the home.

The pivotal role assigned to family members in the rehabilitation process raises important challenges to current perceptions of confidentiality and privacy in medical ethics. Most analyses of confidentiality and privacy maintain that information concerning diagnosis and prognosis is not to be shared with third parties, including family members, unless and until explicit permission has been sought and granted from a patient. But the amount of time involved in the usual course of medical rehabilitation and the important roles that family members are asked or seek to play may require rehabilitation professionals to disclose information to family members in a manner that in other contexts would be considered at best inadvisable and at worst unethical.

The prominent role accorded family members imposes special obligations on rehabilitation professionals. They must make every effort early on in the course of care to identify the nature of the relationships that exist between patients and their families. They must try to ascertain which family members, if any, have ongoing relationships of intimacy and trust with a patient. If patients have close bonds with family members, they should be informed that, for various reasons, it may prove necessary to share information about their diagnosis and prognosis with such individuals. At the same time, family members must be given honest and accurate information about the roles they may be asked to play during the course of rehabilitative care and the choices they will face at the conclusion of rehabilitation efforts.

The need to clarify the moral framework that ought to guide the relationships team members have with patients and their families is made more acute by recent discussions about the desirability of shifting the provision of medical rehabilitation for many patients from institutional to home settings. The desirability of home care seems to rest on three separate ethical values.

First, patients themselves often prefer to reside at home rather than in institutional settings. Second, rehabilitation professionals believe that patient autonomy is enhanced by early discharge to home settings. There is a fear that patients who remain too long in institutional settings will find it more difficult to adjust to life outside the institution. And third, the provision of rehabilitative services in the home or to those who live at home may prove to be an attractive way to reduce the costs associated with hospital or institutional care.

Economic considerations have dominated public policy discussions of the desirability of home care in rehabilitation. Since there are few carefully designed empirical studies of the impact of home care on patient functioning and satisfaction, and since it is, in any event, difficult to know how much weight to assign patient preferences with respect to the setting in which care is delivered, public discourse about the role of families tends to revolve around cost/benefit projections of the savings to be obtained either by discharging patients home more quickly or by delivering services customarily given in hospitals or institutions on an outpatient, ambulatory basis. The level of interest present in professional and public policy discussions in delivering more services in the home or to those who reside at home makes it imperative that the nature and source of moral obligations of family members to provide care be carefully examined.

Despite the diversity of opinions and values that exist in American society about the importance of the family and the obligations, rights and responsibilities that inhere in this social institution, there is widespread consensus as to the existence of an obligation on the part of family members to assist each other when the need for help exists. Parents are expected to help their young children, children are viewed as responsible for providing for the welfare of their elderly parents, and spouses are seen as responsible for assisting each other when problems, medical or otherwise, arise.

The vexing moral dilemma in thinking about familial obligations is not whether a moral foundation is present to ground minimal obligations between family members, but what limits can be set on the degree of obligation family members have. Are there boundaries beyond which health care professionals or public officials cannot in good conscience expect a family member to go? Are there certain tasks so onerous that no policy-maker could legitimately expect a family to feel obligated to undertake, much less for the state to mandate or enforce their discharge? And even if a mother or a husband were willing to care at home for a family member requiring long and arduous rehabilitative care as a consequence of injury to the spinal cord or massive burns, are there certain tasks that ought not to be asked of anyone by health professionals or those who formulate public policy?

The question of the limits, if any, which constrain the obligations of family members to help one another forces a confrontation with the question of whether the relationships that family members have with each other are special or unique. An important psychological reality associated with membership in a loving family or family-like relationship is that membership in a family, either through birth or adoption, or as a result of a voluntary choice as exemplified in marriage, or the decision to reside with another person over a sustained length of time, creates a unique form of interdependency.

Those who have permanent impairments as a result of injuries, diseases or congenital anomalies often require the help of others. Frequently, this assistance can and, if special skill or expertise is required, must be provided by health care professionals. But for those who have long-standing, intimate relationships, there comes a time when the provision of care by strangers will not suffice. For those who are members of families require not only care but care provided by particular persons—the members of their family.

If it is true that patients who have loving relationships with others depend upon family efforts to enhance their chances of gaining access to care, for encouragement in carrying out their treatments, and for assistance once their treatment regimen has ended, then the degree of obligation consonant with family membership is complicated by the special needs those with chronic impairments have to be accepted and cared for by their families. Those with chronic impairment need to regain more than physical or cognitive abilities. They also need to restore their emotional attachments. As a result, the families and friends of those with chronic impairments face unique demands of concern and affection that only they can fulfill.

It is difficult to imagine any theory of morality imposing demands upon family members that are so burdensome as to make the continuation of the family impossible. Similarly, it is difficult to imagine a moral argument that would make it obligatory for a family member to sacrifice everything, all projects, all prospects of personal enjoyment, all fiscal and emotional resources to meet the needs of another member. In great measure, the limits of family obligation are determined by the degree of sacrifice that an obligation imposes on an individual or the threat it poses to the integrity of the family as a whole.

Once it is admitted that family members can meet certain needs that rehabilitation patients have and that they are the only persons who can meet them, certain ethical implications would seem to follow. While health care professionals should not expect moral heroism from families, they do need to explain to them the unique capability they possess in providing care to those with chronic impairment. The capacity of family members to care for their loved ones also would allow for greater degrees of moral suasion on the part of rehabilitation professionals to elicit the sense of obligation to help that family members feel.

At the same time, if family members are to play pivotal roles in the provision of care to those requiring ongoing rehabilitation, then society has a duty to minimize the level of burden imposed on family members who wish to fulfill their obligations to those who need their care. Family members are often willing and eager to help. But their goodwill should not be used as a rationale to avoid allocating insufficient societal resources.

Family members who are called upon to aid patients discharged from institutional rehabilitation settings need both financial and psychological support services. Moreover, it is appropriate for the community to recognize their efforts to fulfill their moral obligations. The provision of services to families may entail costs that make home care a less attractive alternative in the eyes of some public officials. But, rehabilitation professionals who believe that the home is the best setting for enhancing the autonomy of patients and their quality of life should attend to the ethical implications such an approach has for families rather than the financial consequences for society.

Professional and Practice Issues

As previously noted, rehabilitation is unique in the delivery of care by a team of professionals. The utilization of teams of professionals gained popularity during and after World War II. The underlying rationale was that a team approach would provide better coordinated and more comprehensive care than could be given by individual professionals acting independently.

Proponents of a team approach also argued that this form of the delivery of care would result in a more efficient utilization of services. Schedules could be organized and resources provided more efficiently if health care professionals coordinated their efforts.

Finally, a team approach, in which members shared responsibility for care, was seen as consistent with the interdisciplinary, multiprofessional requirements of rehabilitative programs directed toward all aspects of the patient. The members of a team who shared responsibilities for care were likely to have greater respect for the expertise and skills of colleagues than was evident in more traditional, physician-dominated health care.

Teams and Patient Care

One of the more potentially confusing aspects of rehabilitation for new patients and their families is learning to adjust to the interdisciplinary approach used in the delivery of care. Patients usually enter rehabilitation from acute care settings. While many professionals participate in the care of patients in acute care settings, ultimately treatment is directed by a particular physician who is seen as responsible for the quality of care that is provided.

Patients admitted as candidates into rehabilitation programs must readjust their expectations and attitudes to accommodate the commitment of health care professionals to a less hierarchical, coordinated team approach. Patients and their families may not understand who is in charge of their care, or may want to impose a particular conception of professional accountability upon a group of health care providers who are committed to a different manner of providing care. Unfortunately, not all rehabilitation teams are as conscientious as they should be in educating patients, families and friends about the organization and structure of team-based care.

In addition, not all teams function in the same way in rehabilitation. Some operate with a physiatrist who acts as a kind of "captain" of the team. Others attempt a more egalitarian sharing of responsibility among team members with shared authority and accountability for decision-making. Patients may seek to ally themselves with one or another member of the team. In doing so, they may provoke friction among the team itself depending upon the style of management that predominates in a given setting. Team members should be willing to accommodate their preferred style of team management to the desires of particular patients to the extent that the ability of the team to provide care for other patients is not affected adversely.

The members of a successfully functioning team inevitably develop strong feelings of loyalty to other team members. These are individuals who must work closely with one another over long periods of time, and it is natural that when this work is done well fidelity to one's colleagues is both expected and desired.

However, team loyalty poses potential ethical problems for team/patient relationships. Whereas health care professionals in many domains of health care see part of their professional responsibility as acting as monitors of the overall quality of care being provided to patients, it may be very difficult for the member of a team to pursue this objective within the context of a team. Team members may be viewed as disloyal or unethical if they raise issues about the competency of team members or the adequacy of a treatment plan directly with patients. Patients may expect that, if the members of a team say they are to be treated as co-equals in terms of their responsibility for care, they will be able to interact with the team by selecting anyone of the team's members as their advocate, when in fact this may not be so.

Another distinctive aspect of team care is the role team members assign to themselves as providers of care. Health care professionals in rehabilitation often say that they see themselves as educators, teachers, or guides in helping their patients undergo treatment.

But the emphasis upon patient responsibility inherent in the role of teacher or guide is not always consistent with the bureaucratic and efficiency requirements of effectively coordinating the activities of a large number of people. Patients may be told that they must set their own goals and strive to fulfill them, but it is also true that they must do so within the constraints of a team responsible for meeting the health care needs of many patients.

Patients in some rehabilitation units or specialized institutional facilities often are placed on fairly rigid schedules. There are almost always institutional policies governing such areas of daily living as eating, smoking, dressing, television viewing, exercise, and visiting hours that admit of little if any modification or individualization. Despite the fact that team members pride themselves on providing care to the whole patient in an individualized manner that relies on the active participation of patients, many social and economic factors associated with the provision of care by large groups of people in institutional settings are at odds with these aspirations. There is an inevitable tension, exacerbated in recent years by growing concerns about the need to control the high cost of health care, between the desire to have patients take responsibility for their own care, and institutional interests in seeing that care is provided in a manner that is efficient and cost-effective.

Team-based care may well be the most useful mode for delivering the services of large numbers of professionals to individual patients. But those in rehabilitation must be careful not to allow the rhetoric that surrounds the justification of a team approach to obscure some of the tensions that arise when the desire to maximize patient responsibility and participation come into conflict with the need to provide services in an efficient manner.

Interprofessional Issues

Conflicts about the lines of authority between professionals and patients are not the only ethical problems that arise when care is delivered by a team. Inevitably, conflicts of authority and responsibility arise between various members of the team. While ideally teams should function as tightly coordinated groups providing multifaceted individualized courses of treatment, this ideal can be compromised when team members disagree as to the goals appropriate for particular patients or when different members of the team set different priorities among the various goals appropriate for particular patients.

Conflicts between team members over scheduling of treatments, rest periods and free time are a frequent occurrence in rehabilitation facilities. When patients arrive late for appointments or when therapists cancel sessions at the last minute, resentments can arise among team members.

Professional responsibility requires that individual professionals resolve their interprofessional conflicts in light of the needs and interests of their patients. Teams must therefore have administrative mechanisms for the rapid identification and resolution of interprofessional conflict. More importantly, they must routinize these mechanisms so that problems are not allowed to fester in ways that compromise the access patients have to treatment or the quality of care they receive. Team members have an ethical obligation to insure that all members are accountable for their actions to the entire team and a responsibility to insure that effective administrative mechanisms exist for insuring accountability. Each member of the team must be prepared to instigate discussion and review of individual professional behavior when it is at variance with their perception of the care that is in a particular patient's best interest.

Resource Allocation for Medical Rehabilitation

The ethical issues arising at the level of public policy with respect to rehabilitation are no less complex than exist in other areas of health care. With nearly thirty million Americans claiming some level of disability or handicapping condition, and one in ten Americans under retirement age claiming a level of disability sufficient to impair their ability to work, the potential pool of rehabilitation patients is enormous. While precise numbers are difficult to obtain, the number of persons actually receiving medical rehabilitation services is far below the number who might benefit from access to care.

The issue of access is complicated by the high costs associated with providing medical treatment to those with severely disabling injuries or diseases. For example, the average costs associated with the medical rehabilitation of patients who have permanent impairments as a result of head or spinal cord injuries is one hundred thousand dollars. Since there are at least fifty thousand new cases each year of permanently disabling head or spinal cord trauma, the costs associated with rehabilitation for these patients are at least five billion dollars every year. Additional costs are incurred as a result of loss of wages and the need to provide social and income support.

While precise numbers are difficult to obtain, the number of persons actually receiving medical rehabilitation services is far below the number who might benefit from access to care.

As more and more individuals survive spinal cord injuries, head trauma, the life-threatening risks of congenital anomalies and prematurity at birth, as a larger and larger proportion of the American population lives into their seventies, eighties and nineties, the demand for rehabilitation services will continue to escalate. To date, medicine and society have not openly grappled with the moral question of whether those who are rescued or saved by acute care medicine have a legitimate claim to receive the follow-up rehabilitative services that will enhance their capacity to cope with disability. However, whether a decision to rescue does or does not confer a right on the part of those who are saved to an adequate level of follow-up care, it would seem to make sense on utilitarian grounds to insure that efforts at acute care are coordinated with adequate levels of medical rehabilitation.

In recent years rehabilitation hospitals and long-term care facilities have been exempt from some of the efforts to control the escalation of health care costs. They have been specifically excluded from the newly created prospective payment schemes in public and private health insurance. However, as the number of public and private facilities claiming to offer rehabilitative services has escalated, perhaps in response to the perception that greater profits can be earned in the context of rehabilitation than are available in other domains of health care, pressure has grown on those who administer federal health care programs such as Medicare to include rehabilitation as a part of prospective payment. Many rehabilitation professionals are deeply concerned that a reimbursement system designed to meet the contingencies of acute care practice can only be implemented in the context of treating those with chronic disabilities by compromising the quality of care that is provided.

In order to secure increases in public funding, those who would argue that society has failed in its obligation to provide adequate access to minimal levels of medical rehabilitation must be prepared to demonstrate that more patients need medical rehabilitation and that medical rehabilitation is efficacious. Unfortunately, those within the field of medical rehabilitation have not always sought or received sufficient funding to permit efforts to accurately assess levels of need and, more importantly, to demonstrate through controlled scientific trials that the techniques and practices of rehabilitation are indeed efficacious.

If rehabilitation is to retain its relatively privileged status in relation to efforts at cost-containment, and if appeals for greater resources for medical rehabilitation are to be heeded, then those in the field have an ethical obligation to demonstrate the need for and the efficacy of the skills, techniques and technologies that are currently being utilized. Current estimates of need are closely linked to current patterns of utilization. But these estimates reveal little about who might benefit if more resources were allocated to medical rehabilitation.

At a time when competition for resources in health care is especially fierce, there is insufficient funding available for the collection and analysis of data in a systematic fashion concerning the efficacy of rehabilitation interventions. Since a key element in eliciting a sense of obligation on the part of the public to provide greater access to and a higher quality of rehabilitative care is to show that medical rehabilitation is beneficial, the demonstration of efficacy is one of the strongest obligations health professionals in the field have relative to matters of resource allocation.

Pedagogical Issues

While a number of institutions and professional societies have made some concerted efforts in recent years to introduce topics in ethics into their educational programs, a great deal remains to be done if the ethical issues facing practitioners in rehabilitation medicine at the clinical and policy levels are to be adequately addressed. These efforts must be made in a number of different educational settings.

Training Professionals

Very few professional schools in medicine, nursing, allied health, or social work offer courses in the area of rehabilitation ethics. In part, this is a result of the fact that there is little in the way of case materials or substantive articles that take rehabilitation medicine as their focus. In part, faculty members have not been encouraged to make ethics a focus of research or teaching.

If rehabilitation ethics is to be taken seriously as a necessary and vital component of the education of students in professional school settings, then faculty members must be encouraged and given time to acquire the knowledge required to teach the subject. Debates over who should teach courses or where in the curriculum they should be offered are less important than whether competent and committed professionals are available to do the teaching.

While accrediting agencies in rehabilitation do not place an emphasis on formal teaching in ethics, it is interesting to note that some professions such as nursing have chosen to do so. Similarly, specialties such as internal medicine, family medicine, and pediatrics have introduced an ethics requirement into their board certification processes.

Ironically, requirements concerning ethical conduct were once a part of the certification process for rehabilitation professionals but legal concerns regarding liability appear to have led to their removal as a formal educational requirement. Serious consideration should be given by appropriate groups within rehabilitation to the desirability of adding formal certification requirements in the area of ethics for both schools and specialty training programs as the availability of teaching materials and qualified instructors in the area of rehabilitation ethics increases.

There are a variety of settings in which greater attention can be directed toward ethical issues in rehabilitation. Journal editors should encourage more writing on both clinical and policy topics bearing on ethics and medical rehabilitation. Conference organizers at the local, national and international levels should solicit symposia and panel discussions of appropriate topics.

The introduction of ethics committees at many institutions provides a useful forum for the discussion of ethical issues in clinical rehabilitation. Frequently, these groups are assigned the task of sponsoring workshops or rounds on medical ethics. Rehabilitation professionals should work closely with these committees to facilitate more attention to ethical problems of the sort that arise in medical rehabilitation.

Finally, rehabilitation professionals must work more closely with groups and organizations in the community to facilitate discussions of ethical issues in rehabilitation. Trustees, patient and family advocacy groups, and staff and officials from major charitable organizations need to be educated as to the nature of the ethical challenges now confronting and soon to be confronting providers and patients in rehabilitation medicine.

Greater efforts need to be made within the bioethics community to incorporate rehabilitation medicine into ongoing research, teaching, and professional society activities. The emphasis on acute and emergency medicine so much in evidence in the current literature of bioethics needs to be supplemented with more cases and analyses based on problems arising in the context of rehabilitation and related areas of chronic care medicine.

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Differing Approaches to Prevention of Disability and Treatment of Impaired Infants Creates Controversies Worldwide

Reprinted from the International Rehabilitation Review, Vol. XL, Nos. 2 & 3

In the last year there have been developments in Europe, Asia and the Pacific and North America which illustrate the depth of disagreement among groups in society about appropriate approaches to prevention of disability. Examples are: in China a provincial law has been passed barring mentally retarded people from having children and a law is being drafted to extend the ban nationwide; a European conference on ethical issues and mental retardation was cancelled in response to protests from advocacy groups; a French group has petitioned the European Parliament to, in essence, make it legal for doctors and parents to withhold treatment and sustenance from disabled infants; in the U.K. this spring a case brought to the highest courts resulted in a media uproar about how treatment decisions concerning impaired infants are made; and in the USA a series of conferences on ethics and disability prevention and rehabilitation continues to reveal deep-seated differences among advocacy groups, the medical profession and parent groups.

Catalysts

These developments have been catalyzed by a variety of factors: as the technological machinery to detect disabling conditions before birth becomes more sophisticated and less expensive to apply universally, pressure mounts to establish national policies or laws about its application; a spate of "cost-benefit" studies contrasting the costs of disability detection and prevention with life-long support systems have caught the attention of some politicians and administrators responsible for controlling escalating health system costs; and the addition of "quality of life" considerations to debates about health care rationing and costs has brought to the surface major differences of opinion about who has the right to evaluate another's "quality of life" and based on what criteria.

New Technologies vs. Society?

The 20th century has been characterized in part by the rapid development of technologies put into effect before society has been ready to absorb them. The arsenal of medical technologies which could now be deployed to prevent disability in utero for the most part prevent the birth of a child. This forces the disability field to confront squarely what its and society's beliefs are about the value of life with a disability. At present the most often expressed opinions range from disability advocacy groups which believe that prevention of disability by prevention of births is, in effect, genocide, to groups which believe that if practical information about life with a disability is provided by genetic counsellors that decision-making can be vested with parents, to groups who believe that decision-making should be based on economic considerations and be vested in governmental policies.

Chinese law

The Chinese provincial legislature of Gansu adopted in November a law forbidding retarded citizens to marry without first undergoing sterilization, requiring those who are married to be sterilized and requiring severely retarded pregnant women to undergo abortions. According to the *International Herald Tribune* (November 26-27, 1988) there was heated argument over the legislation when it was proposed in July. An official from the Ministry of Public Health was quoted as saying that a similar national law is now being drafted.

French Organization

A controversial French organization, the Association for the Prevention of Handicap in Childhood (APEH) has placed a petition (no. 357/88) before the European Parliament, proposing a "bill to reduce the number of abnormal births." The proposal, based on the rationale of economic burden to the country and psychological burden on the affected household, calls for the decriminalization of the withholding of treatment and sustenance of infants who "will never have any true quality of life." The proposal also states that two doctors and the parents or guardians involved should agree on the decision.

European Meeting

A European regional meeting on ethical issues in the mental retardation field was planned by Lebenshilfe, a parent-oriented group based in the Federal Republic of Germany. Following protests and threats of demonstrations against the discussion of euthanasia on the conference agenda, the meeting was cancelled. The protest groups took the position that for the leading organization in mental handicap to sponsor a meeting including this topic and featuring speakers whose views are believed to be in favor of euthanasia was in effect to offer support to the practice.

"Baby C", England

In England in April major media attention was focused on how treatment decisions are reached concerning infants with severe impairments. Known as "Baby C", the case revealed wide differences of opinion on how the medical profession, courts and parents should interact to decide on whether aggressive or passive treatment is indicated. A spokesman for Mencap, the leading mental handicap charity, said that the case highlighted the need for an ethics committee to take fundamental decisions, within a clear legal framework within which all available evidence can be considered and all those who know the child would be heard. (*The Guardian*, April 21)

Bioethics, USA

In the USA, many heated conferences have been held in the last few years under the aegis of bioethical concerns, a rapidly growing profession. Beginning in the late 1960's with the founding of the Hastings Center, there are now hundreds of bioethics organizations worldwide. Increasingly, concerns about medical treatment for infants and the elderly with severe disabilities have been a focus for these groups.

Leading bioethicists have expressed concern about the future direction of the new field. Daniel Callahan, a founder of the Hastings Center, stated recently that the field is being deflected from essential "big questions" about the purposes and limits of medicine, science and ultimately, human nature, and is entering a regulatory phase. The Rev. Richard John Neuhaus, a Luthern minister prominent in sociomedical issues, recently called bioethics "the Permissions Office of contemporary medical and biological science." (*New York Times*, Ideas and Trends, June 25, 1989)

Section 5
Annotated International Bibliography

Ethical Issues and Disability

An International

Annotated Bibliography

Prepared by International Disability Exchanges and Studies (IDEAS) Project, administered jointly by World Institute on Disability and Rehabilitation International. This listing is not intended to be comprehensive and reflects only material available in RI files. We will welcome additions.

A Overviews/Conference Proceedings

America's Health Care Revolution: Who Lives? Who Dies? Who Pays? by Joseph A. Califano, Jr., published 1986 by Random House, Inc., New York, NY 10022, $17.95 hardcover, 241 pp. Califano shows how well-intentioned efforts of government, employers, and unions to assure care have encouraged waste, greed, and fraud. He demonstrates how spiraling costs endanger not only our health care system but also the social fabric of the nation as we confront the explosive growth of our elderly population. He describes the rise of America's medicine men and women, their high-tech hospitals, and the host of scientific and biomedical breakthroughs with their promise of miracle cures and threat of unacceptable costs.

Biomedical Ethics: An Anglo-American Dialogue, Ed. Daniel Callahan, G.R. Dunstan, published 1988 by Annals of the New York Academy of Sciences, Volume 530, 2 East 63rd St., New York, NY 10021, USA, $46, 175 pp. Papers from 1987 conference of same name on: I) A Tale of Two Cultures: Understanding Cultural Similarities and Differences; II) The Delicate Balance: Ethics, Law and Medicine; III) The Nature of the Physician-Patient Relationship; IV) The New Reproductive Technologies: Are We Creating New Ethical Problems?; V) Treatment Decisions Regarding Serioudly Ill Newborns; VI) The Privatization of the Health Care System; VII) Age as a Criterion in TReatment and Allocation Decisions; VIII) Ethical Issues in Human Subjects Research; IX) Mass Screening, Civil Liberties, and the Public Health; and X) A Look to the Future.

"Children in the Tropics", Issue No. 79 on *Genetics and Health*, International Children's Centre, Château de Longchamp, Bois de Boulogne, 75016 Paris, France, subscription US$25 per year (six issues). Special issue on genetic pathology as it relates to Third World countries.

Critical Issues in Medical Technology, Barbara J. McNeil and Ernest G. Cravalho, Auburn House Publishing Company, 131 Clarendon Street, Boston, MA 02116, USA, 1982, $28.00 hardcover, 432 pp. This book explores the influences of successful biomedical technology-based innovations and the pivotal role played by hospitals in adopting new technologies. It points out the pitfalls and biases in evaluating new screening, therapeutic, and diagnostic techniques and the social and ethical implications of technology, and presents an overview of the ways health care costs are affected by new technologies and their regulation.

"Ethical Considerations in the Life of a Child with Down Syndrome", Siegfried M. Pueschel, M.D., Ph.D., M.P.H., *Issues in Law & Medicine*, Vol. 5, No. 1, Summer 1989, pp. 87-100, Office of Publications, P.O. Box 1586, Terre Haute, IN 47808-1586, USA. Analyzes the ethical issues in the life of a child with Down syndrome.

Ethical Issues in Caring, Edited by Gavin Fairbairn and Susan Fairbairn, published by Gower Publishing Company, Old Post Road, Brookfield, VT 05036, USA, 1988, $44.95 hardcover, 180 pp. This book emerged from the Ethical Issues in Caring conferences between the years 1982 and 1986. It includes papers on: Profession and vocation; Nursing: A paradigm of caring; On the concept of nursing care; On not caring about the individual; Shall we care for you or do you want to work?; Paternalism and caring; Respecting feelings; Ethical confrontation in counselling; Choice in childbirth; Towards an institution of surrogacy; Needs and justice in health resource allocation; Community social work and the limits of commitment; Quality of life and services of people with disabilities; and, Psychotherapy: deliverance or disablement?

"Ethical Issues in Teamwork: The Context of Rehabilitation,", Ruth B. Purtillo, Ph.D., *Archives of Physical Medicine and Rehabilitation*, Vol. 69, May 1988. Discussion of how team approach, when guided by well-formulated moral policies, provides ample opportunities for the rehabilitation candidate's best interests to be served. Reprints: Ruth B. Purtilo, Ph.D., Massachusetts General Hospital, 15 River Street, Room 410, Boston, MA 02108, USA.

Ethics and Human Values in Family Planning, edited by Z. Bankowski, J. Barzelatto and A.M. Capron, published 1989 by the Council for International Organizations of Medical Sciences (CIOMS), c/o WHO, 1211 Geneva 27, Switzerland, Sw Fr 20, 308 pp. Conference highlights, papers and discussions of the XXII CIOMS Conference on the above subject held in Bangkok, Thailand, 19-24 June 1988. Divided into the following five subjects: 1) Highlights; 2) Ethical, scientific and legal perspectives; 3) Regional differences; 4) Reports of the working groups; and 5) Reflections of the conference.

"Ethics Education: A Literature Review", by Jeanne Boland Patterson, College of Education, 215 Stone Building, FLorida State University, Tallahassee, FL 32306, USA, *Rehabilitation Education*, Vol. 2, pp. 121-128, 1988. The paucity of literature on teaching ethics in rehabilitation education suggests that ethics may not be given the curricular emphasis it needs. This article reviews the literature on ethics education in other fields, describes common misconceptions which counter the importance of ethics education, and offers specific recommendations for rehabilitation educators.

Ethics of Dealing with Persons with Severe Handicaps: Toward a Research Agenda, edited by Paul R. Dokecki and Richard M. Zaner, published by Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624, USA, 1986, $21.95 softcover, 294 pp. This presents an open forum for discussion of the moral issues surrounding the research and interventions pursued for persons with severe mental retardation and other handicapping conditions. Focusing on moral and practical issues, ethicists, theologians, special educators, psychologists, physicians, and lawyers speak on the present state of affairs and the key subjects needing immediate attention.

The Ethics of Genetic Control: Ending Reproductive Roulette, by Joseph Fletcher, published 1988 by Prometheus Books, 700 East Amherst St., Buffalo, NY 14215, USA, $15.95 softcover, 218 pp. In this book Fletcher explains why some accepted ethical values need to catch up with the science of human reproduction, and why new reproductive methods can be more "normal" than those they replace.

"Families as Caregivers: The Limits of Morality," Daniel Callahan, Ph.D., *Archives of Physical Medicine and Rehabilitation*, Vol. 69, May 1988. Psychologic and moral problems that confront family caregivers are examined. Reprints: Daniel Callahan, Ph.D., The Hastings Center, 255 Elm Road, Briarcliff Manor, NY 10510, USA.

"The Future Has Arrived For Bioethics, and It's a Profession Now," by Peter Steinfels, *New York Times*, June 25, 1989. A look back at the field of bioethics from its beginning and the opening of the Hastings Center to its current status and the problems associated with its rise to prominence.

"The Gene Hunt," Leon Jaroff, *Time Magazine*, March 20, 1989, pp. 38-43. Description of $3 billion project launced by National Institutes of Health to map chromosomes.

Health Policy, Ethics and Human Values: an international dialogue, proceedings of XVIIIth Council for International Organizations of Medical Sciences Round Table Conference, Athens, Greece, 29 October-2 November 1984, Sw Fr 25, 336 pp. Main fields include: bioethics; international nomenclature of diseases; drug development and use; health manpower; and, health policy. Available from: WHO, 1211 Geneva 27, Switzerland.

Health Policy, Ethics and Human Values: European and North American Perspectives, edited by Z. Bankowski and J.H. Bryant, published by the Council for International Organizations of Medical Sciences (CIOMS), c/o WHO, 1211 Geneva 27, Switzerland, 1988, Sw Fr 20, 221 pp. Conference highlights, papers and conclusions of the XXIst CIOMS Conference in Noordwijk aan Zee, The Netherlands, 2-5 June 1987.

"Human Dignity and Professional Self-Monitoring," Beatrice A. Wright, *Journal of Applied Rehabilitation Counseling*, Vol. 18, No. 4, 1987, pp. 12-14. The author addresses the meaning of human dignity as it relates to the counselor-client relationship. This concept is seen as an underpinning of all ethical standards.

"An Introduction to Ethics," Ann L. Plamondon, *AMICUS*, May/June 1979, pp. 118-119. Discussion of incompatibility between concepts termed "respect for persons" versus "beneficence," "self-determination" ("autonomy") versus "protection," and "sanctity of life" versus "quality of life" which stems from two radically different approaches to ethical questions.

"Made-to-Order Babies", Geoffrey Cowley, *Newsweek*, Special edition on the 21st Century Family, Winter/Spring 1990.

"Medical Ethics in Europe," *Theoretical Medicine*, Kluwer Academic Publishers Group, P.O. Box 322, 3300 AH Dordrecht, The Netherlands, Vol. 9 No. 3, October 1988, $116.50 per volume. Contains papers on Medical Ethics in Britain, France, Federal Republic of Germany, Finland, Sweden, Norway and Poland.

"The Perils of Treading on Heredity," Philip Elmer-Dewitt, *Time Magazine*, March 20, 1989, pp. 44-45. Comment on possible ethical and moral effects of unlimited tampering with DNA.

"Public Attitudes Toward Disabled Persons as Reflected in Public Laws," David Pfeiffer, Ph.D., Department of Public Management, School of Management, Suffolk University, Boston, MA 02108, USA, 1989, 21 pp. Minorities, women, and disabled people face statutorily based discrimination today although discrimination based upon a handicapping condition is usually thought to stem from attitudes, not laws. It is argued in this paper that negative public attitudes toward disabled people are reflected in public laws. The statutes of the various states and territories are examined for laws which are examples of statutorily based discrimination against disabled persons. Strong support is found for the proposition that discriminatory public attitudes are reflected in public laws today.

Success and Crisis in National Health Systems: A comparative approach, edited by Mark G. Field, published 1989 by Routledge, Chapman & Hall, 29 West 35th Street, New York, NY 10001, USA, $45 hardcover, $18.95 softcover (296 pp.). Using a cross-national, comparative framework, scholars from different countries examine the various aspects of health care and provide analyses of the factors that have brought serious problems along with the abundant achievments.

"Value-Laden Beliefs and Principles," Beatrice A. Wright, Preface to Second Edition of *Physical Disability: A Psychosocial Approach*, Harper & Row, 10 E. 53rd Street, New York, NY 10022, USA, 1983. Discussion of the author's "value-laden beliefs and principles" offered as possible guidelines with the intent that they be examined and improved.

B Medical/Medico-Legal Aspects

Borrowed Time: Artificial Organs and the Politics of Extending Lives, Alonzo L. Plough, Temple University Press, Broad & Oxford Streets, Philadelphia, PA 19122, USA, 1986, $24.95 hardcover, 214 pp. Acting as a patient-observer, Plough critiques the social and political problems of artificial organs and provides insight into how medical technology shapes patient and physician experiences.

"Ethical and Policy Issues in Rehabilitation Medicine: A Project Summary 1985-1987," Arthur L. Caplan, Hastings Center, 360 Broadway, Hastings-on-Hudson, NY 10706, USA. Report of Hastings Center of two year study to examine the ethical and policy challenges posed by rehabilitation medicine.

"Ethical issues in the treatment of cancer patients," D.J. Roy, *Bulletin of the World Health Organization*, Vol. 67, No. 4, pp. 341-346. Discussions and recommendations of the Ethics Working Group of the international conference on Supportive Care—More than Medicine held in Canada in 1988.

"Ethics and Health Policy," *WHO Features*, No. 111, September 1987, World Health Organization Media Service, 1211 Geneva 27, Switzerland. How many heart bypass operations should a national health authority undertake in a given year? How many kidney dialysis machines should it buy and operate? What proportion of the authority's budget should be earmarked for the growing number of elderly people in the community? Overview of CIOMS Conference in Noordwijk, Netherlands.

"Ethics in Rehabilitation Medicine," Janet F. Haas, M.D., Moss Rehabilitation Hospital, Philadelphia, PA 19141, USA, *Archives of Physical Medicine and Rehabilitation*, Vol. 67, April 1986. Ethical dilemmas of chronic illness and rehabilitation medicine must be addressed lest we compromise health care, patient autonomy, provider effectiveness and the country's commitment to care properly for its disabled individuals.

European Code of Medical Ethics, World Medical Association, 28, Avenue des Alpes, 01210 Ferney-Voltaire, France, 18 July 1986.

"Genetics, Medicine and Ethics," Zbigniew Bankowski, *World Health*, December

1988, pp. 3-5, WHO, Av. Appia, 1211 Geneva 27, Switzerland. Bankowski advocates early education in order to guarantee responsible use of genetic engineering.

"Informed Consent and Provider-Patient Relationships in Rehabilitation Medicine," Arthur L. Caplan, Ph.D., *Archives of Physical Medicine and Rehabilitation*, Vol. 69, May 1988. Discussion of legitimacy of paternalism in health care relationships. Cites instances when paternalistic care is ethically justified. Reprints: Arthur L. Caplan, Ph.D., Center for Biomedical Ethics, University of Minnesota, Box 33 Mayo Bldg., Minneapolis, MN 55455, USA.

"The Islamic Perspective in Medical Ethics," by Shahid Athar, *Hamdard Medicus*, Vol. XXXII, No. 2, April-June 1989, Hamdard Foundation Press, Pakistan, Hamdard Centre, Nazimabad, Karachi-18, Pakistan, US$20 annual subscription, US$5 single copy. Because of the growing Muslim population in the USA, American physicians will have to deal with medical ethics concerning their Muslim patients. This article is an attempt to present the Islamic perspective as mentioned in Quran, the Holy Book of Islam.

Issues in Law & Medicine, Vol. 5, No. 3, Winter 1989. The following relevant articles appear in this issue:

> "The Psychological Impact of Disability and Illness on Medical Treatment Decisionmaking," Daryl Evans, Ph.D. An original research report on the psychological impact of disability on medical treatment decisionmaking to compare the attitudes of parents of children with spina bifida, physicians, and neonatal intensive care unit nurses against the legal background of the Child Abuse Amendments of 1984.
>
> "Does Autonomy Require Informed and Specific Refusal of Life-Sustaining Medical Treatment?", Fenella Rouse, J.D. Argues that autonomy fails to function as a practical model in right to die decisions.
>
> "Does Autonomy Require Informed and Specific Refusal of Life-Sustaining Medical Treatment?", Gerard V. Bradley, J.D. Analyzes the concept of autonomy and argues that neither the constitutional law nor the common law supports the lethal choices approved by some courts in right to die decisions.
>
> "Rationing Health Care: Will It Be Necessary? Can It Be Done Without Age or Disability Discrimination?", Daniel Callahan, Ph.D. Proposes an age based rationing standard as the best alternative to a difficult problem.
>
> "Rationing Health Care: Will It Be Necessary? Can It Be Done Without Age or Disability Discrimination?", Marshall B. Kapp, J.D., M.P.H. Contends that rationing health care by age is unconstitutional and unethical.

Journal of Head Trauma Rehabilitation, special issue on ethical and legal issues, Aspen Publishers, Inc., 7201 McKinney Circle, Frederick, ND 21701, USA, single copies $17.50, Vol. 4 No. 1, March 1989. Articles include: "Societal duty and resource allocation for persons with severe traumatic brain injury," Gerben DeJong, Ph.D. and Andrew I. Batavia, J.D., M.S.; "Legal and ethical issues in the psychopharmacologic treatment of traumatic brain injury," D. Nathan Cope, M.D.; "Neurorehabilitation and HIV infection: Clinical and ethical dilemmas," Vivian Auerbach, Ph.D. and Brigitta Jann, M.D.; "Ethical Issues and families of brain-injured persons," Mary D. Romano, ACSW;

"The assessment of clinical competency to consent to medical rehabilitative interventions", William J. Haffey, Ph.D.; "Legal guardianship in traumatic brain injury rehabilitation: Ethical implications," Thomas P. Anderson, M.D. and Margaret S. Fearey, Esq.; "Videotaping therapeutic sessions and the right of privacy," by John D. Banja, Ph.D. and Patricia Higging, MS, CCC-Sp.

Medical Genetics for Health Professionals, Stanley Kaplan, Ph.D., Health Sciences Consortium, Inc., 200 Eastowne Drive, Suite 213, Chapel Hill, NC 27514, USA, 1981, 54 pp.

NYU Physician, special issue on "Ethical Challenges in Medicine," Vol. 45 No. 1, Fall 1988, NYU School of Medicine, 550 First Avenue, New York, NY 10016, USA, single copies $7.50. Sections include: Ethical Issues in Patient Care; Ethical Issues in Health-Care Policy; Ethical Issues in Medical Education; and Medical Ethics in History.

World Hospitals, September 1988, Canadian Hospital Association, 17 York Street, Suite 100, Ottawa, Ontario Canada K1N 9J6, subscriptions £37 per year. Articles on: "Technology: servant or master?" Dr. H.J. Warrick; and "The ethics of resource allocation," Erica Bates.

C Pregnancy/Reproductive Technology/Women's Issues

"Abortion in Context," Adrienne Asch, *The Women's Review of Books*, Vol. III, No. 2, November, 1985. Asch reviews the book *Abortion: Understanding Differences*, edited by Sidney Callahan and Daniel Callahan, New York: Plenum Press, 1984, 338 pp. $35.00 hardcover. The book in review is a collection of ten essays, five with pro-choice viewpoints and five with those of pro-life.

Choices, Not Chances: An Essential Guide to Your Heredity and Health, Aubrey Milunsky, M.D., published 1989 by Little, Brown, and Company, 205 Lexington Ave., New York, NY 10016 for $22.50, 520 pp. A guide to the risks of inheritable diseases, covering genetic counseling, diagnostic tests, gene tests for genetic disorders, causes of birth defects and mental retardation and many other disorders.

"Discrimination Linked to Genetic Screening," by David Goodman, in *American Medical News*, June 9, 1989.

"In India, They Abort Females," Jo McGowan, *Newsweek*, January 30, 1989. Editorial on ethical opposition to abortion using India as example of misuse.

"In-Vitro Fertilization and Embryo Transplantation," June 1987, proposed World Medical Association Statement, 28, Avenue des Alpes, 01210 Ferney-Voltaire, France.

"The Modern Scourge," S.N. Gajendragadker, paper presented at RI 16th World Congress, Tokyo, Japan, September 1988. Female foeticide in India. Available from: Japanese Society for Rehabilitation of the Disabled, 5F, Rasai-Kaikan, 20-8, 7 Chome Nishi-Shinjuku, Shinjuku-ku, Tokyo 160, Japan.

"Perfect Mothers, Perfect Babies: An Examination of the Ethics of Fetal Treatments," Caroline L. Kaufmann, Ph.D., *Reproductive and Genetic Engineering*, Vol. 1 No. 2, pp. 133-139, 1988. Medical technology often is employed to reinforce and sanction existing social roles. In this context, society's acceptance of fetal surgery sanctions women in their role as gestators and enforces their social obligation to bear healthy babies.

"Reproductive Technology and Disability," Adrienne Asch, *Reproductive Laws for the 1990s*, edited by Sherrill Cohen and Nadine Taub, Humana Press, Clifton, New Jersey, 1989, pp. 69-124. Asch sketches out the social context for disability in our society and then discusses from the perspective of disability rights the six areas of reproductive concerns: prenatal screening, time limits on abortion, fetus as patient, reproductive hazards in the workplace, alternative modes of reproduction, and interference with reproductive choice.

The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood, Barbara Katz Rothman, published by Viking Penguin Inc., 40 West 23rd Street, New York, NY 10010, USA, 1986, $17.95 hardcover, 274 pp. Rothman examines the impact of prenatal diagnosis upon mothers and motherhood, drawing on the testimonies of over 120 women who experienced amniocentesis. A combination of medical data and firsthand reports, the book includes an Appendix of Guidelines for Personal Decision-Making.

"Uncertain Futures," Adrienne Asch, *The Women's Review of Books*, Vol. IV, No. 2, November, 1986. Review of *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood*, by Barbara Katz Rothman, New York: Viking, 1986, 274 pp. $17.95 hardcover, which reports on a study she made of 120 women who have faced some of the dilemmas posed by amniocentesis, the major available form of prenatal diagnosis.

"Which Information Obtained from Fetus Should be Conveyed to Parents?" M. Kida paper presented at RI 16th World Congress, Tokyo, Japan, September 1988. Results o research questionnaires sent to Japanese medical universities and institutions. Available from Japanese Society for Rehabilitation of the Disabled, 5F, Rasai-Kaikan, 20-8, 7 Chome Nishi-Shinjuku, Shinjuku-ku, Tokyo 160, Japan.

"Women's Health Issues," Adrienne Asch, *Health Policy Advisory Center Bulletin*, Volume 16, Number 6, pp. 6, 8-10. The author discusses her belief that newborns with disabilities should be given appropriate medical treatment regardless of their parent's wishes, even if that treatment requires state intervention, and at the same time provides a basis for her belief in abortion rights.

D Infants

AAMR Journal, June 1986, containing such articles as: "Target '88: Closure of all Special Schools," Judy Baird; "Newborn Children: Medical and Legal Predicaments," Hon Justice M.D. Kirby; and "The Severely Disabled Infant: A Study in Human Rights," P.H. Bailey.

"Agreement on Principles of Caring For Disabled Infants," January/February 1984. *Programs for the Handicapped*, Clearinghouse on the Handicapped, Dept. of Education, Office of Special Education and Rehabilitative Services, Office of Information and Resources for the Handicapped, Washington, DC 20202, USA. Set of principles endorsed by: Association for Retarded Citizens, American Academy of Pediatrics, Spina Bifid Association of America, Down's Syndrome Congress, National Association of Children's Hospitals and Related Institutions, Association for the Severely Handicapped, American Association on Mental Dericiency, American Association of University Affiliated Programs and American Coalition of Citizens with Disabilities.

Disability Studies Quarterly, Brandeis University, Department of Sociology, Waltham, MA 02254, USA, Vol. 7 No. 2, Spring 1987. This issue highlights material relating to "Baby Doe" and other neonatal and early childhood experiences of those with "severe" disabilities.

"Down on Law: The Attitudes of Parents and Physicians Regarding 'Baby Doe' Legislation," Daryl Evans, Ph.D., Department of Sociology, Bureau of Child Research, University of Kansas, Lawrence, KS, USA, paper presented for Society for Disability Studies meeting 16 June 1988, Washington, DC. Examines data from a three year study inquiring into the relationship between legal standards and treatment/nontreatment decisions about children born with spina bifida cystica.

"Ethical and Legal Problems in Rehabilitation and Medicine, 1985." Prof. Gunnar Dybwad, Heller School, Brandeis University, Waltham, MA 02254. Discussion of legal and ethical problems related to the termination of life of infants with disabilities.

"Final Rules Protecting Infants," *Programs for the Handicapped*, Clearinghouse on the Handicapped, Dept. of Education, Office of Special Education and Rehabilitative Services, Office of Information and Resources for the Handicapped, Washington, DC 20202, USA. Summary of the final rules to protect the civil rights of handicapped infants as published in the January 12, 1984 *Federal Register.*

"Guidelines to follow when a child is born with a disability," Barbara Mc Cann, *Interaction, Vol. 1, Issue 5, November 1987*, AAMR Publications Service, GPO Box 647, Canberra ACT 2601, Australia. This protocol outlines a procedure for telling parents that their new baby has a disability, the basis management of the family in hospital and the creation of links with community services who will take major responsibility for support the child and the family.

"The Infant with Anencephaly: Moral and Legal Dilemmas", Debra H. Berger, R.N., *Issues in Law & Medicine*, Vol. 5, No. 1, Summer 1989, pp. 67-86, Office of Publications, P.O. Box 1586, Terre Haute, IN 47808-1586, USA. Focuses on the ethical issues involved in the use of newborns with anencephaly as organ sources for other infants needing transplantation.

"Life and Death and the Handicapped Newborn", C. Everett Koop, M.D., Sc.D., *Issues in Law & Medicine*, Vol. 5, No. 1, Summer 1989, pp. 101-113, Office of Publications, P.O. Box 1586, Terre Haute, IN 47808-1586, USA. Candid view of the right to treatment for infants with disabilities based upon author's extensive professional experience with neonatal surgery.

"Loss of the 'Perfect' Child and Ethical Decision Making: Miguel's Story", by Zola D. Golub, from *Dying and Disabled Children:* Dealing with Loss and Grief, edited by Harold M. Dick, David Price Roye, Jr., Penelope R. Buschman, Austin H. Kutscher, Boris Rubinstein, and Frances K. Forstenzer, published 1989 by The Haworth Press, Inc. 10 Alice Street, Binghamton, NY 13904-1580, USA, $24.95 hardcover, 153 pp. Questions which arise at the birth of a child with multiple abnormalities.

"MDs, Not Parents, End Up Making 'Baby Doe' Decisions" by Diane M. Gianelli, *American Medical News*, American Medical Association, Chicago, December 2, 1988.

"The Oblivion Express: Gender Differences in Focal Concerns and Experiences of Parents Faced with a Treatment or Nontreatment Decision of a 'Baby Doe' ", Daryl Evans, Ph.D., unpublished paper, available from Daryl Evans, Ph.D., Department of Sociology, Bureau of Child Research, University of Kansas, Lawrence, KS 66045-2172.

Examines the differential considerations and experiences characterizing women and men confronted with a treatment/nontreatment decision about an infant with a life-threatening medical condition, which, if treated successfully, would leave the child with severe disabilities, and if left untreated, would have a high probability of leading to the child's death.

Playing God in the Nursery, Jeff Lyon, published by W.W. Norton & Company, Inc., 500 Fifth Avenue, New York, NY 10110, USA, 1985, $18.95 hardcover, 366 pp. Account of legal, social, moral, scientific, and economic implications of decisions to withhold treatment from severely handicapped newborns–an issue that prompted the federal government to set up a Boby Doe hotline. Reports of parents, doctors, nurses and bioethicists, in addition to the disabled adults and children who have been most affected by such judgements.

"Public Policy and Disabled Infants: A Sociopolitical Perspective," Harlan Hahn, Ph.D., Issues in Law & Medicine, Vol. 3, No. 1, 1987. Discussion of the growing interest in the development of public policy to achieve an environment designed to meet the needs and interests of people with disabilities rather than requiring disabled individuals to adjust and adapt to the demands of their present surroundings.

"A Right to Treatment or a Right to Die?" Ronald M. Soskin and S. John Vitello, *AMICUS*, May/June 1979, pp. 120-126. Analysis of the various positions on the issue of the right of "defective" newborns to receive medical treatment essential to the preservation of their lives.

Should the Baby Live? The Problem of Handicapped Infants, by Helga Kuhse and Peter Singer, published by Oxford University Press, Walton Street, Oxford OX2 6DP, England, 1985, $8.95 softcover, 228 pp. This book presents a philosophical analysis of this controversial subject based on particular case studies. Authors examine some actual cases where decisions have been reached; consider the criteria for making these decisions; investigate the differences between killing and letting die; compare Western attitudes and practices with those of other cultures; and conclude by proposing a decision-making framework.

Societal Provision for the Long-Term Needs of the Disabled in Britain and Sweden Relative to Decision-Making in New-Born Intensive Care Units, by Rev. Ernle W.E. Young, Ph.D., monograph published 1984 by World Rehabilitation Fund, (International Exchange of Experts and Information in Rehabilitation), 400 E. 34th Street, New York, NY 10016, USA.

E Aging/Euthanasia/Dying

"Daniel Callahan, Ph.D.: Ethicist causes controversy, advocates denying Medicare funding to extend life of the elderly," Dennis L. Breo, *American Medical News*, February 19, 1988, pp. 33-37. Profile of Callahan, founder of the Hastings Center, a think tank that examines the emerging ethical issues in medicine.

Death Criteria: a report, The Danish Council of Ethics, first annual report, 1988, Ravnsborggade 2-4, DK-220 Copenhagen N, Denmark, 49 pp., free of charge. Report of the Council, an advisory body to the Danish Parliament's Committee on the Council of Ethics and the Minister of Health, which can advise the scientific-ethical committees about general ethical questions in connection with experiments involving human subjects.

"Do You Trust Your Family To Decide When You Should Die?," by Nat Hentoff, *Village Voice*, January 9, 1990. More on "quality of life" debate, with Nancy Cruzan (New York, 1989) case as basis.

"Dying at the Right Time: A Critical Legal Theory Approach to Timing-of-Death Issues", by Sandra Segal Ikuta, J.D., *Issues in Law & Medicine, Vol. 5, No. 1, Summer 1989, pp. 3-66,* Office of Publications, P.O. Box 1586, Terre Haute, IN 47808-1586, USA. Ikuta subjects the entire spectrum of state statutes and cases regarding the right to die to a thorough critical analysis.

"'Elegant way' of dying?" by Harris Meyer, *American Medical News*, American Medical Association, August 4, 1989. Discussion of policies of euthanasia in several European countries.

"Into the Night: The Struggle for a good death," Cortney Davis, *Social Issues & Health Review*, January 1987. A nurse-practitioner's view on euthanasia.

"Life-Sustaining Technology and the Elderly," Allen I. Goldberg, M.D., F.C.C.P., *Chest*,94/6, December, 1988, pp. 1277-1982, reprints from Dr. Goldberg, Medical Director, Respiratory Care, Children's Memorial Hospital, Chicago, IL 60614, USA. This report brings together opinions from medical experts in focus groups about a variety of issues raised by the Office of Technology Assessment in their study of implications of life-sustaining technology and the elderly.

"Michigan quadriplegic earns right to die," Mike Williams, *American Medical News*, August 4, 1989. Article on David Rivlin's fight for his right to have his respirator disconnected.

"Problems of Aging in a Changing World," by M. Abdussalam, *Hamdard Medicus*, Vol. XXXII, No. 2, April-June 1989, Hamdard Foundation Press, Pakistan, Hamdard Centre, Nazimabad, Karachi-18, Pakistan, pp. 21-31, US$20 annual subscription, US$5 single copy. Prepared for a seminar on Health Policy—Ethics—Human—Values—Islamic Perspectives, held in Egypt in 1988.

Serving the Underserved: Caring for people who are both old and mentally retarded, Edited by Mary C. Howell, Deirdre G. Gavin, Gerard A. Cabrera and Henry A. Beyer, published 1989 by Exceptional Parent Press, 1170 Commonwealth Avenue, Boxton, MA 02134, USA, $29.95 softcover, 508 pp. The materials describe the provision of care for a group of patients—people who are both old and mentally retarded—who can be seen to represent all who are underserved, overlooked, and demeaned by cultural prejudice.

F Rationing of Resources, Care and Services

"Admission to Rehabilitation Centers: Selection of Patients," Janet F. Haas, M.D., *Archives of Physical Medicine and Rehabilitation*, Vol. 69, May 1988. Information about the process of selection of rehabilitation candidates, guideliens delineating standards for admission to rehabilitation centers. Reprints: Janet F. Haas, M.D., Temple University School of Medicine, Philadelphia, PA 19140, USA.

"Ethics and Disability Services," *Rehab Brief*, Vol. XII, No. 7 (1989), National Institute on Disability and Rehabilitation Research. Available from PSI International, Inc., P.O. Box 5186, Arlington, Virginia 22205, USA. This issue of *Rehab Brief* attempts to distill and clarify the philosophical substrates of ethical standards in rehabilitation and independent living service delivery and to show how they undergird providers' decision making on critical issues within the field.

"Justice in the Allocation of Public Resources to Disabled Citizens," Baruch A. Brody, Ph.D., *Archives of Physical Medicine and Rehabilitation*, Vol. 69, May 1988. Examines several crucial questions concerning justice in the allocation of public resources to disabled citizens. Challenges the current failure to means-test certain programs, and argues that fundamental choices about levels of funding and about priorities in nonentitlement programs cannot be justified without a better theory of social justice. Reprints: Baruch A. Brody, Ph.D., 1 Baylor Plaza, Houston, TX 77030, USA.

"Quality-of-life Research in Rehabilitation," *Rehab Brief*, Vol. XI No. 1, PSI International, Inc., 510 North Washington St., Falls Church, VA 22046, USA. This Rehab Brief summarizes selected efforts of researchers studying quality of life as well as several definitions of same.

"Recent Developments in Rehabilitation Giving Rise to Important New (and Old) Issues and Dilemmas," The Rehabilitation Institute of Chicago, 345 East Superior Street, Chicago, IL 60611, USA, 1986, 25 page pamphlet. Speech by Dr. Robert Meier, III, delivered at the Rehabilitation Institute of Chicago in April 1985.

Rehabilitation Ideology and Respiratory Support Technology, 40 page paper by Joseph M. Kanfert, Ph.D. and David Locker, Ph.D., available from Kaufert, Dept. of Community Health Sciences, University of Manitoba, 750 Bannatyne Ave., Winnipeg, Manitoba R3E OW3 Canada.

G Viewpoints of People with Disabilities and their Parents/Families

"Elizabeth Bouvia, Assisted Suicide and Social Prejudice," Paul K. Longmore, Ph.D., *Issues in Law & Medicine*, Vol. 3 No. 2, Fall 1987, pp. 141-168. This article concentrates on the historical and contemporary experience of disabled people in relation to assisted suicide.

"Physically Disabled People Assess the Quality of Their Lives," Nancy Weinberg, Ph.D., *Rehabilitation Literature*, January-February 1984. Research study of the issue of life quality made by questioning individuals with disabilities about their lives.

H Parallels Between Eugenics Movements and Genetic Engineering

"The Extermination of Handicapped People in World War II Germany," Wolf Wolfensberger, *Mental Retardation*, Training Institute for Human Services Planning Leadership and Change Agentry, 805 South Crouse Avenue, Syracuse University, Syracuse, NY 13210, February, 1981. The seemingly obscure facts regarding the program of extermination of handicapped and mentally retarded persons in World War II Nazi Germany are reviewed. Possible parallels between the experiences in Germany and contemporary developments are suggested.

"Feats to Concoct the Flawless Being," Charlotte Low Allen, *Insight*, July 11, 1988. A different form of eugenics has emerged in recent years: genetic engineering of one's own offspring. Discussion of current attempts to manipulate the gene pool.

"German Doctors and the Final Solution," Robert Jay Lifton, *New York Times Magazine*, September 21, 1986. Excerpt from *The Nazi Doctors: Medical Killing and the Psychology of Genocide*, Basic Books.

"The New Genocide of Handicapped and Afflicted People," Wolf Wolfensberger, Training Institute for Human Service Planning, Leadership & Change Agentry, 805 South Crouse Avenue, Syracuse, NY 13244-2280, USA, 1987, 114 pp.

"The Psychiatric Holocaust," Peter Roger Breggin, M.D., *Penthouse Magazine*. Paper states that German psychiatry played the single most important role in developing the ideology and practice of mass sterilization and mass murder.

I Other

"European Communities European Parliament Session Documents", Document A 2-0327/88, Series A, 19 December 1988, photocopies available for US$10 to cover costs from Rehabilitation International, 25 East 21st Street, New York, NY 10010, USA. Report drawn up on behalf of the Committee on Legal Affairs and Citizen's Rights on the ethical and legal problems of genetic engineering.

A Guide to Selected National Genetic Voluntary Organizations, National Center for Education in Maternal and Child Health, 38th and R Streets, NW, Washington, DC 20057, USA, 1989, 223 pp. A directory of mutual support groups concerned with the medical and psychosocial impacts of genetic disorders and birth defects on affected individuals and families. The entries are arranged according to categories of disorders. An organization index and a subject index are included.

Medical Technology Assessment Directory, National Academy Press, 2101 Constitution Avenue, N.W., Washington, DC 20418, USA, 1988, $250.00, 712 pp. Director includes a cross-listing so that a number of reports on a given technology can be seen at once. Includes references to work in "fugitive" areas that might not be easily found elsewhere.

Mental and Physical Disability Law Reporter, Commission on the Mentally Disabled, American Bar Association, 1800 M Street, N.W., Suite 200, Washington, D.C. 20036, USA, individual subscriptions (six issues) $140 year. Journal which provides information on recent court decisions, case updates, legislative and regulatory developments, timely articles, legal analyses and periodic statutory reviews.

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